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INSTITUTO DE CIÊNCIAS DA SAÚDE
LISBOA·PORTO·VISEU

INTERNSHIP IN PALLIATIVE CARE
in the Palliative Care, Pain Therapy and Rehabilitation Unit. FONDAZIONE IRCCS - ISTITUTO NAZIONALE DEI TUMORI, MILAN, ITALY

FINAL REPORT

Report submitted to The Catholic University of Portugal as a requirement in full for the degree of Masters in Palliative Care

By
Ana Leonor Vasconcelos Vilar Cadete de Matos

Lisbon, 2018

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Under the Supervision of
Augusto Caraceni, MD

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“ONE OF THE DEEP SECRETS OF LIFE IS THAT ALL THAT IS REALLY WORTH DOING IS WHAT WE DO FOR OTHERS”

Lewis Carroll

SUMMARY

The possibility to work for three months in *Istituto Nazionale dei Tumori* in Milan gave me the opportunity to develop practical skills in Palliative Care, which I felt I lacked. It also provided me the chance to work in a renowned institution, side by side with specialists with a vast experience in providing advanced holistic care to cancer patients. The opportunity was both appealing and challenging. My main goals were: to develop skills in the comprehensive assessment of pain and other symptoms from cancer and its treatment; to monitor patients for adequacy of symptom relief; to improve communication techniques mainly in illness understanding, prognosis and end of life; to learn more about clinical research in palliative care and if possible, to participate in clinical studies, and finally to integrate multidisciplinary teams in different settings of palliative care provision.

During my 3 months' internship in the Palliative Care, Pain Therapy and Rehabilitation Unit, I've worked in the Outpatient Clinics, Day Hospital, Hospice, Inpatient Consultation Team and Home Care Team, and I have also developed research work within the Department.

I value this experience as it changed my perception of Palliative Care, and reassured me that this subject of medicine is rigorous, based on robust evidence, and has a remarkable impact in quality of life and survival of patients living with advanced illness. I've worked dedicatedly to this final report in order to describe, in the most realistic way, what drives me, which are my goals, and how I've achieved them during this internship. The research project concerning palliative sedation resulted in an article published in the *Journal of Pain and Symptom Management*.

In the end, I feel that I've benefited immensely from this experience, gathering skills and competences to improve palliative care in my daily practice and to give my contribution to the delivery of top quality palliative care in my country.

Key Words: Palliative Care, Cancer patients, Symptom control, Palliative sedation

RESUMO

A oportunidade de trabalhar no *Istituto Nazionale dei Tumori* em Milão teve origem na vontade de desenvolver competências em Cuidados Paliativos que sentia em falta, e a ideia de o fazer numa Unidade de renome, com especialistas experientes na prestação de cuidados avançados e holísticos a doentes oncológicos, foi para mim cativante e desafiante. Os principais objetivos por mim delineados foram: desenvolver competências na avaliação detalhada da dor e de outros sintomas derivados do cancro e das suas terapêuticas; monitorizar a adequação do alívio sintomático; melhorar técnicas de comunicação, nomeadamente no entendimento da doença, prognóstico e fim de vida; acompanhar e participar em projetos investigação clínica em cuidados paliativos; integrar as diferentes equipas multidisciplinares em diferentes contextos da prestação de cuidados paliativos.

Durante o meu estágio de 3 meses na Unidade de Cuidados Paliativos, Controlo da Dor e Reabilitação, trabalhei na Consulta Externa, Hospital de Dia, *Hospice*, equipa intra-hospitalar e cuidados domiciliários, tendo ainda desenvolvido trabalho de investigação dentro deste Serviço.

Valorizo esta experiência pelo modo como alterou a minha perceção dos Cuidados Paliativos, reafirmando o quanto esta área da medicina é rigorosa, baseada em evidência robusta e como a sua aplicação tem um impacto notável na qualidade de vida e sobrevivência da pessoa com doença avançada.

Trabalhei dedicadamente na elaboração deste relatório, procurando descrever de modo realista o que me motiva, quais são os meus objetivos e como os alcancei durante este estágio. O trabalho de investigação desenvolvido no tema da sedação paliativa resultou num artigo publicado no *Journal of Pain and Symptom Management*.

No final, sinto que aproveitei ao máximo esta experiência, reunindo aptidões e competências para a melhoria dos cuidados paliativos na minha prática diária, procurando assim contribuir para a prestação de cuidados paliativos de elevada qualidade no meu país.

Palavras-Chave: Cuidados Paliativos, Doente oncológico, Controlo sintomático, Sedação Paliativa

ACKNOWLEDGMENTS

A great part of the unforgettable experience I had in my 3 months in Milan, I owe it to people. I owe it of course to every person in whose life I was allowed to enter. Besides their illness, their frailty, their suffering, they've accepted me into their privacy, and with them I've learned so much. But I also owe it to the many others that took part in this history and to whom I therefore I am infinitely grateful :

To Manuel Luís Capelas, for giving me the idea to go to *Istituto Nazionale dei Tumori* (INT), for allowing it to become real and for believing in me and in my will to become a Palliative Oncologist.

To all the professors of Catholic University, for their commitment to the students, for their rigorous teaching of Palliative Care subjects and for encouraging us to contribute to the development of quality Palliative Care in Portugal.

To Augusto Caraceni, for allowing me to work with him and his incredible team, for guiding me, teaching me and inspire me to keep working in this field.

To Luigi, Francesca, Silvia, Riccardo, Federica, Tiziana and Paola, they made me feel I was part of the team. Thank you for your daily dedication to patients, for inspiring me in doing the same, for helping me and teaching me. To them, but also to all the INT Palliative team, who welcomed me and integrated me, I am forever grateful.

To the best friends I could ask for, thank you for your constant support and affection.

To my life companion, Eduardo, thank you for your endless love and permanent presence, no matter how apart we are.

A word of tremendous gratitude to my family, my parents, my brother, my grandparents. You've made me who I am. Thank you for always believing in me and for allowing me to follow my dreams. You are my cornerstone and biggest inspiration in life.

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ABBREVIATION KEY

ADL – Activities of Daily Living

BTAs – Bone Targeted Agents

DH – Day Hospital

EAPC – European Association of Palliative Care

ECOG – Eastern Cooperative Oncology Group

ESMO – European Association of Medical Oncology

INT – *Istituto Nazionale dei Tumori*

NRS – *Numeric Rating Scale*

OC – Outpatient Clinics

PC – Palliative Care

PS – Performance Status

QoL – Quality of life

INTRODUCTION

The history of Palliative care begins with the attention given to the care of the dying. In the 1960s, Dame Cicely Saunders established the modern hospice movement in the United Kingdom, based on the careful observation of terminally ill patients (1). With a great sense of humanity and a strong determination, Dr. Cicely Saunders raised awareness on the importance of preserving dignity and quality of life of patients with incurable illnesses, advocating at the same time the need to empower research and training in this area. As brilliantly described by David Clark in the Foreword of the book "Watch with me" (2), Cicely Saunders held on her life's work an enduring preoccupation: a concern for the relationship between personal biography, the spiritual life and ethics of care. Contemporaneously, Elizabeth Kübler-Ross, an American psychiatrist, defended the urge to treat people in the end of life with respect, openness and honest communication (1). In 1974, Dr. Balfour Mount coined the term "palliative care" to label his hospital-based service (3), and introduced Saunders' innovations into academic teaching hospitals (1). Since then, palliative care has evolved from a philosophy aimed at improving care for terminal patients, to a professional specialty that provides comprehensive care for patients and their families.

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Cancer is the second leading cause of death worldwide, and the disease which incidence has increased the most. In 2015, 1/6 of all causes of death worldwide were due to this illness that we tend to call as "modern", because it was in the last decade that it has taken its leading role, as a result of industrialization, control of infectious diseases and the increase of life expectancy in developed countries. In fact, in the last century we've almost duplicated lifespan and augmented cancer incidence in 30%.

Cancer was first described during the Hippocratic period, using the term *Karkinos* from the Greek work "Crab". This word originated from the similarity that Hippocrates found between this crustacean, buried in the sand with its legs open and a protruding mass with filled blood vessels around. Nevertheless, it was the Greek word *onkos*, usually

used to describe tumors, that originated the modern term of oncology. It meant “mass” or “burden”(4). Cancer was therefore seen as a burden that the body carried. However, Hippocrates and his initial conception of cancer were far to resemble the entity we now know.

Cancer represents a wide group of diseases with high complexity and variability, originated from the process of carcinogenesis. This concept defines a sequential model according to which cancer develops, inexorably, from a small and localized tumor, to an advanced disease which progresses to metastasis and, in its natural history, to death. In this process, there are now well recognized distinct capabilities that cells have to acquire do gain advantage and to proliferate, which have become the targets to the development of early detection methods and personalized therapies, intended to be minimally deleterious to the host.

But talking about cancer will always and above all be to talk about people. Only the word makes us tremble, wishing that this scourge doesn’t knock at our door. We connect this terrible disease to suffering. And no one wishes to suffer. And so the biggest challenge in dealing with people with cancer will be how to best address and alleviate their needs.

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Being a medical oncologist in practice has been teaching me a great deal about human suffering. It has also made me realize that being an oncologist is as much about knowing the disease and how to manage it, as about mastering symptom relief and providing an active supportive care to the patient and to the family. Moreover, addressing the emotional, social and spiritual needs of the person has showed me to be equally important as approaching the physical ones, in order to achieve an adequate relief of suffering. From an educational perspective, I’ve learned the importance of recognizing and assessing “total pain”, Dame Cicely Saunders’s concept that incorporates physical, emotional, social and spiritual domains (5).

However, despite the need to offer patients a meaningful, rigorous and individualized care, physicians are often more comfortable dealing with the medical and

fact-based realms (6), lacking an honest communication with the patient and the families, that encompasses their needs. Doctors tend to focus on the patient's disease, not on the person. The magnitude of this issue rises as it is not restricted only to cancer patients, but to the majority of the severe and chronic illnesses of our time. People will live all their lives with that illness, and with a tremendous burden of distress (7). And so, the question imposes: what are we doing to relieve that burden?

In Portugal, a lot of work has been undertaken in the last years towards giving shape to the World Health Organization' definition of palliative care: "an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual" (8). Despite the efforts, there are still important differences in needs of palliative care and a significant asymmetry in the coverage of these needs (9). Besides, as stated by Dr. Diane Meier, in many settings the little palliative approach that is being offered, is to terminal patients. But the majority of patients who need palliative care, aren't dying (7).

As I felt impelled to work towards the improvement of Palliative Medicine in my country, I felt the need to learn more. During my first year as a resident, I started searching for training and learning opportunities, and underwent a post-graduate course in grief and bereavement and also an advanced course in pain management. Through this path, I started my palliative care masters in the Catholic University in Lisbon in 2016.

To obtain the master's degree, the choice of doing a research-project or a clinical-practice internship is offered. In the beginning of the classes, with the opportunity to study palliative care, the ideas were bursting in my head and the prospect of developing a research project was appealing. Nevertheless, I felt it wouldn't fulfil my needs of developing practical skills I felt I lacked, and that would be crucial to what is my daily practice. Also, as I wish to integrate palliative care teams, I felt essential to learn on the field, with skilled teams, so I could give a meaningful contribution. Moreover, I presumed that, if I chose the right place to make an internship, I would have the opportunity to develop research competences that also felt to be critical for my construction as an

oncologist and palliative care practitioner. After sharing my goals with my Master's professor Manuel Luís Capelas, the idea of applying to an internship in INT in Milan came immediately and, with his help, I was accepted to work in the Palliative Care Department of this Institute for 3 months.

This report pretends to describe the activities developed in my 3 month internship in INT. It is organized in 4 sections: General goals and expected learning outcomes; Internship Host Institution; Internship Description; Conclusions and Final Remarks. In the first section I will describe the main goals I've set to this internship, as well as skills and competences I expected to acquire. In the "Internship Host Institution" section, I'll describe briefly the history of Palliative Care in Italy and the role of INT in developing this field. Then, I intend to describe thoroughly how each section of the Palliative Care, Pain Therapy and Rehabilitation Unit is established, how it works and who comprises each team. In the third section, my aim is to report the activities in which I was enrolled in each section of the Unit during my internship and to describe the observed population, in terms of characteristics and opportunities to learn from them. In Final Remarks and Conclusions , I acknowledge the impact of this internship in my practice, how the proposed goals were met and the path I intend to follow having acquired this amount of experience.

The Vancouver style of referencing was applied in this report

1. GENERAL GOALS AND EXPECTED LEARNING OUTCOMES

GENERAL GOALS

Before the beginning of my internship, I've established the following goals based on two important documents for an oncologist resident that wants to develop advanced skills and competences in Palliative Care: The ESMO / ASCO Recommendations for a Global Curriculum in Medical Oncology Edition 2016 (10) and the White Paper from de EAPC on Core competencies in Palliative Care (11). These four main goals will be the basis of my training in a high-level Palliative Care Unit.

- Symptom management and control – To be able to screen, assess, prevent and manage different symptoms (such as pain, fatigue, delirium, malignant bowel obstruction, nausea and breathlessness), by following senior doctors and nurses in different settings (outpatient clinics, inpatient consultation team, hospice, home care), and to learn with their approach to patients' symptomatic issues. Also, I would like to acknowledge and address differences in what concerns the type of patients and their phase in the disease trajectory, according to setting. Particularly, I will try to understand the types of medications used and other existing therapeutic approaches, as well as difficulties encountered, for example, by the inpatient consultation team when addressing patients' symptoms.

- Psychosocial and spiritual approach - To meet patients psychological, social and spiritual needs, and the ones of their families. To approach family as unit of care. To be involved in a multidisciplinary approach in these fields, learning how to assess and manage these matters, also developing and improving effective communication skills about illness understanding, prognosis and end-of-life preparation. The department team comprises, besides doctors and nurses, psychologists, physiotherapists, chaplain, shiatzu professional, social assistant, volunteers, neurology consultant. My goal here will

be to understand the importance of each of these specialists for the approach of the psychological and spiritual dimension of each patient, and how, in a practical way, it improves the quality of the provided care.

- System implementation and functioning – To gain awareness about a complex and well established palliative care system, how it is structured, how it works, and how it is integrated in the community. To this, I will gather oral information provided by the teams that work in the different departments and settings.

- Research – I will work in a Palliative Care Unit in which the research field is extremely well known for its quality and high–standard research, centered in improving patients' well-being and quality of life. Here, I would like to dedicate some of weekly working hours for getting involved in research work, essentially in clinical and translational settings, and to develop some research work, or help developing some ongoing research project, this to be decided with the research team accordingly to the available time.

EVALUATION INDICATORS/ EXPECTED LEARNING OUTCOMES

Knowledge, skills and competences to be acquired

- Appreciation of the role of palliative care interventions across the trajectory of illness for patients with cancer;
- Recognition of the effects of palliative care interventions integrated into decision-making for anticancer treatments;
- Familiarity with the role of multidisciplinary approach in the care of patients with advanced cancer;
- Ability to contribute actively in a structured way in a multidisciplinary team to plan and manage care for patients and their families;

- Ability to screen and to perform a comprehensive assessment of main symptoms (pain, dyspnea, fatigue, anorexia, nausea, delirium, depression, anxiety, diarrhea, constipation), as well as competences-based management
- Ability to elaborate and discuss an integrated plan of care;
- To recognize the unique aspects of end-of-life care, such as decision-making processes, symptom management, involvement of family members and spiritual aspects;
- To understand and be able to approach main issues of end-of-life care, beyond symptom control, such as legacy, finishing business, grief, with patients and with their families;
- Ability to communicate efficiently with patients and their families and other caregivers, discussing main issues, preferences, desires and fears, and to manage them;
- To be able to identify criteria, such as triggers, for referral to specialized palliative care teams;
- To identify clinical issues and matters that represent gaps requiring integrated research.

2. INTERNSHIP HOST INSTITUTION - THE PALLIATIVE CARE, PAIN THERAPY AND REHABILITATION UNIT OF *ISTITUTO NAZIONALE DEI TUMORI*

The Palliative Care Unit of *Istituto Nazionale dei Tumori* in Milan retains the history of palliative care in Italy. The movement was initiated in the 70's, under the initiative of professor Vittorio Ventafridda. It was with the good will and financial support of non-profit organizations and private charities like The *Floriani* Foundation, and the Italian League Against Cancer, that palliative care become a reality. The first progresses started at the homecare level, mainly due to organizational, economic, social and cultural reasons. It was in the 90's that palliative care became established and legislated, and that a national plan on organization of these services was designed. In 2001, palliative care became recognized as an essential level of assistance, obliging this care to be provided to the population, for free, according to a structured model of network assistance (12). In the last years, palliative care in Italy is continuously developing, with the improvement of palliative home care teams, covering most of the territory, and also with the creation of a substantial number of hospices, with the Lombardy region accounting for the majority (13). The first hospital hospice comprised in a scientific institute was born in 2006, in *Istituto Nazionale dei Tumori di Milano*, named Hospice *Virgilio Floriani*, thanks to the support of this Foundation. Currently, The Palliative Care, Pain Therapy and Rehabilitation Department of INT in Milan is a referral Centre for palliative care both nationally and internationally, that brings together academics, healthcare professionals, the community, caregivers and patients, with a multidisciplinary team dedicated to providing high quality support and best possible quality of life for cancer patients and their families.

Nowadays, the Palliative Care, Pain Therapy and Rehabilitation Unit of *Istituto Nazionale dei Tumori*, comprises different sections, with specialists who provide assessment and management of cancer-related symptoms, loss of function and family support, having as main goal the restoration of optimal patient functioning in multiple life domains, including physical, social, emotional and spiritual. During my internship I had

the opportunity to accompany work in the following services:

- Outpatient Clinics;
- Day Hospital;
- Inpatient Consultation Team;
- Hospice;
- Palliative Home Care Team.

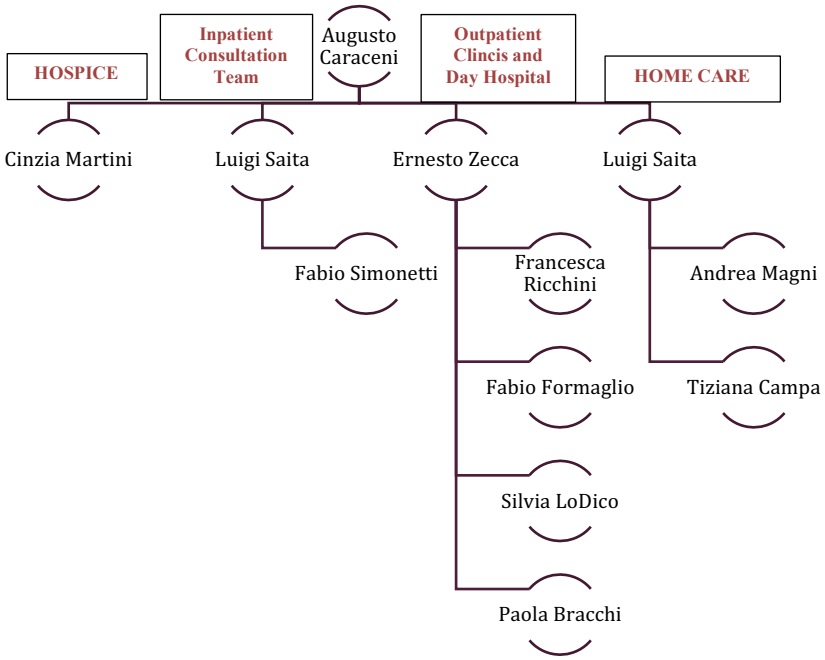

Figure 1- Diagram of the Palliative Care, Pain Therapy and Rehabilitation Unit team

Figure 1 tries to illustrate the organization of the medical staff working in the Palliative Care, Pain Therapy and Rehabilitation Unit of INT. It is, however, important to point out that this was the organization during my stay in the Unit, but the divisions are not fixed, meaning that some doctors rotate between different departments occasionally, so they keep developing work in each of the departments. For example, Dr. Cinzia Martini is the supervisor of the Hospice, but sometimes Dr. Silvia LoDico can be working with her. Also, for example, Dr. Paola Bracchi works in Hospice, but she can also be repositioned in the Home Care Team. Therefore, most doctors in this Unit have a deep knowledge of how every setting works and are adaptable to each of them.

2.1. OUTPATIENT CLINICS

The PC Outpatient Clinics (OC) provides outpatient PC services in INT. It comprises medical offices, the day hospital of PC with specialized nurses and a doctor assigned, rehabilitation services and psychology and psycho-pedagogy assistance.

It works from 8 am to 5 pm, weekdays, being assured by 4 medical specialists, and an Outpatient Clinics coordinator:

- Ernesto Zecca, M.D. – Outpatient Clinics Coordinator
- Francesca Ricchini, M.D.
- Silvia LoDico, M.D.
- Paola Bracchi, M.D.
- Fabio Formaglio, M.D.

The patients referred to the OC come essentially from other departments in the Institute: Medical Oncology, Surgery, Radiotherapy, being referred mainly patients with poor symptom control and with advanced-stage disease. Most of the patients that are referred have stage IV disease, so they are not receiving cancer-specific therapy with curative intent, being mostly under palliative intent therapy or under best supportive care. Treatment-related symptoms are managed mostly in the Supportive Care in Cancer Unit. Therefore, the majority of symptoms that are assessed and treated in the Outpatient Clinics are most often tumor-related, consequence of past treatments, or due to other non-yet clarified motives.

Moreover, thanks to early Palliative Care referral models, the Clinics seeks to avoid late referrals to Palliative Care. These models try to identify patients who meet appropriate criteria, and incorporate, besides type of cancer, cancer staging and place of metastases, symptom burden, functional capacity, psychological impact and social support. The importance of early referral of cancer patients to palliative care has been a target of extensive research in the last years. One of the most remarkable studies is the randomized clinical trial by *Temel et al* (14), published in 2010, with an outstanding impact in the perception of Palliative Care. This study was carried out in patients with metastatic non-small cell lung cancer, and compared standard cancer treatment versus

cancer treatment with concurrent palliative care started in the 8 weeks following the diagnosis. This study not only met its primary goal of improvement in quality of life of patients receiving early palliative care compared with patients only receiving standard oncologic care, but also showed how it reduces aggressive treatments in the end of life, as chemotherapy treatments, emergency departments visits, hospitalizations and time in hospice. But maybe the most unexpected and therefore publicized result was the increased survival of cancer patients when receiving early palliative care. More evidence exists supporting this data (15–17), and therefore confirming how an early and simultaneous approach to the cancer patients increases their quality of life, their endurance throughout cancer treatment, their acceptance of the clinical situation, as well as it allows a constant support and assessment of needs, essential for challenging decisions in more advanced phases of the disease and in the end of life.

In the Outpatient Clinics, one example of an integrated model of referral, concerns the attention to bone health and the prevention of complications related with bone metastases, mainly skeletal events, bone pain and hypercalcemia. Therefore, every patient with bone metastases is referred to the Outpatient Clinics, in order to receive bone targeted therapy, when no contraindications exist, with the adequate follow-up and interventions, whenever necessary. Among these, I would highlight periodical assessment of calcium and vitamin D, with supplementation when necessary, and assessment of renal function to adequate hydration or dose adjustment. To prevent a rare but important complication of the administration of drugs, the osteonecrosis of the jaw, every patient undergoes a visit to the stomatologist and orthopantomography to assess dental health. The results of the establishment of a protocol in INT for odontoiatric prevention of osteonecrosis of the jaw in patients under bisphosphonates therapy was published in 2008 in Annals of Oncology (18), reporting a 75% reduction in this adverse event.

In the Outpatient Clinics, each appointment has a predicted duration of 20 minutes. The frequency of visits depends on a variety of factors, mainly symptom control, therapeutics monitoring and degree of disease progression and expected clinical deterioration. Each appointment is written down informatically in a pre-designed model

that comprises: Motif of the appointment; Diagnosis; Clinical synthesis (with anamnesis and physical exam); diagnostic procedures, diagnostic and treatment prescriptions, and next appointment. The assistance provided to cancer patients in the Outpatient Clinics is an example of the importance of early referral to adequate symptom management and to the prediction and prevention of adverse outcomes. The OC works closely with the other sections of the PC Unit, ensuring adequate referral to different setting, as Hospice or Home Care, whenever needed.

2.2. DAY HOSPITAL OF PALLIATIVE CARE

The Day Hospital (DH) of Palliative Care works every weekday from 8 am to 3 pm, and is integrated in the Outpatients Clinics, being under the same coordination. It is an open space with 6 armchairs and 3 beds, a working room for nurses and a cabinet for doctors. The DH has a capacity to enroll between 25 to 30 patients at a time.

Here, patients come referred mainly by the Palliative Care Team itself: whether by the home care team or by the OC. The Day Hospital provides crucial assistance since it allows the provision of immediate support in terms of symptom control, with the opportunity to perform several therapeutics in different ways of administration (intravenous, intramuscular, subcutaneous). For patients that come with, for example, uncontrolled pain, immediate relief, opioid titration and rotation are all possible tasks to be performed. Furthermore, when there is need to undergo intravenous hydration, ionic reposition, diuretic therapy, corticosteroid therapy, blood transfusion or bone targeted therapy, all these can and are performed in this setting. Diagnostic and therapeutic procedures can also be performed in DH, like ultrasound-guided paracentesis, thoracentesis, as well as placement of long duration catheters to drain ascites or pleural liquid. Frequently there's also need to collect blood samples to check, for example, for anemia, signs of infection or ionic disturbances justifying new or worsening symptoms.

The DH team comprises 4 skilled nurses, an assistant Doctor and one doctor in training, as well as a technical assistant. Together, doctors and nurses make a clinical evaluation of all patients in every visit, monitoring mostly symptom control, and

developing a treatment plan. With every patient's visit to the DH, nurses fill in the Morse fall scale (19) (Attachment 1) for identifying fall risk factors, make an evaluation of patient's autonomy in daily activities, and complete the ESAS scale, validated to the Italian language by researchers of the Palliative Care team of the Institute (20,21) (Attachment 2). All this information is recorded in the written file of each patient and updated to each visit.

It is important to point out that families are also a fundamental part of the decision-making process, when addressing different aspects of care for patients with advanced disease in DH. With the patient's consent, families can be present all the time, and involved in the clinical process, giving an important contribution to the understanding of symptom burden, limitation in ADLs and more social or psychological dimensions that are not always perceptible in DH assessment. In DH, it is usual to undergo family conferences, together with the social assistant and the psychologist. These are opportunities to discuss critical decisions of the advanced care planning, as deciding for home care or hospice, defining priorities and approaching end-of-life issues. The anticipation of critical events is also crucial and makes part of the whole process. Activation of home care assistance or transference to hospice is a common procedure initiated in the DH setting.

The Outpatient Clinics, together with the Day Hospital, undoubtedly represent an example of an organizational model with a profound impact in QoL of patients and their families, being also an open door to approach and manage the multifaceted aspects of care.

2.3. INPATIENT CONSULTATION TEAM

The inpatient consultation team of INT is composed by a medical doctor, Dr. Luigi Saita, and nurse Federica Rusconi. Both work every weekday from 9 am to 4 pm. The consultation team assesses inpatients throughout the institution, when requested by each hospital department, helping with symptom control, evaluating appropriateness and need for rehabilitation services, assisting in discharge planning and developing an appropriate plan of care that's within the patient and the family's needs.

The inpatient consultation team is also a bridge between palliative care services and every surgical and medical hospital department. The team provides a direct route to admit patients into different palliative care sectors at discharge (as outpatient clinics or home care), as well as in transferring patients to hospice, when meeting adequate criteria, namely considerable symptom burden that requires constant monitoring by a specialized palliative care team and terminal patients.

2.4. HOSPICE

Hospice *Virgilio Floriani* in INT is a tribute to the priest and founder of the *Floriani* Foundation, who financed the construction of this sector. The infrastructures where the hospice is localized, comprise also the headquarters of the Palliative Care Department, with medical and research private offices, secretary, meeting room and working space for the PC team. The Department is linked to the hospice through two different doors, one that goes directly to one of the Hospice corridors, and other that goes to the nurses' working space.

The Hospice is provided with 10 individual rooms with private bathrooms, TV-screen, a desk, a closet and sofa bed, as well as shared spaces: a kitchen, a living room, a room for reading, and a small open terrace with table and chairs.

The Hospice team is, once again, multidisciplinary and consists of doctors, nurses, psychologist, psychopedagogist, physiotherapists, occupational therapists, shiatzu therapist, chaplain and social assistant. Hospice is a very particular setting, where providing total care is an everyday goal. Symptom control, psychological support, advance care planning, coordination of care and development of coping strategies are provided under the best and most updated evidence, with several concluded and ongoing clinical trials that aim to contribute to improve the quality of the provided palliative care.

The well-being of patients that come to the Hospice is one of the key concerns. The harmony of the space stands out, with plants along the corridors, and silence or some peaceful music. Often some cultural events take place in hospice, like concerts, reading clubs, or movie projection.

2.5. PALLIATIVE HOME CARE TEAM

At the time of my internship, the palliative Home Care Team comprised a team of 3 doctors, 5 nurses, a physiotherapist, a psychologist and a social assistant. The team works every week day from 8 am to 4 pm, being on call after that, and also during night periods and weekends. Patients followed by this team are referred mainly from the Outpatient Clinics or Day Hospital, but also after Hospice discharge or by the inpatient consultation team. The Palliative Home Care Team works in the areas around INT, being that each doctor and nurse is responsible for some areas, and provides assistance to patients living in the areas assigned for them. Medical visits happen, usually, twice a week, but the periodicity depends on level of assistance. Each patient is classified as having need of high, medium or low level of medical assistance, being this classification very dynamic, meaning a patient can pass from medium level for high level in a week, needing daily doctors and nurses' visits. The periodicity of nurse's visits also depends on this classification and is usually more frequent than doctors' visits, going from twice daily to weekly.

It is maybe needless to say that a patient can only be referred to the Palliative Home Care Team if they have a caregiver responsible for them. In fact, a key factor for the success of the work developed by the Home Care team is the autonomy provided to family and caregivers in the assistance to the patient. To all the caregivers, a first home appointment is made, with the doctor and nurse assigned for that patient, in which all the team functioning is explained, phone numbers provided, as well as clarification of doubts, fears and concerns about having a patient with an advanced illness at home. A complete anamnesis and physical exam are also performed. In this appointment, a bag with different kinds of medication is given to the caregiver, with a thorough explanation of their purpose, dose, frequency and way of administration. A subcutaneous catheter is placed in every patient, and instructions about how to administer each drug provided through this way are provided to the caregiver (Attachment 3). A complete assessment of needs is also made in this appointment, both physical, social, psychological and spiritual, and meeting these needs will be one of the main concerns of the team

(Attachment 4). In the following visits, reassessment of those needs, symptom management and assistance to family and caregivers will be given, among other tasks that are variable depending on each case. Blood exams are made whenever necessary and therapeutic scheme readjusted if needed. The team aims to decrease the number of visits to the emergency department made by these patients, trying to prevent and to anticipate more difficult situations, instructing caregivers on how to act in specific situations, always with the support of the Palliative Team.

2.6. RESEARCH ACTIVITIES

The Palliative Care Department of INT has a long reputation in developing well-design research trials, published in high impact Journals, that provide critical evidence to support practices in the field of Palliative Care. Furthermore, the Department organizes periodical training and scientific activities, both nationally and internationally and is also the headquarters of the Palliative Care Research Centre and of the Research Network of the European Association for Palliative Care (EAPC). The Department contributes actively for the organization of the Congress of the Italian Society of Palliative Care (*Società Italiana di Cure Palliative - SICP*) and the Congress of EAPC.

The main responsible for the research work in this Department is Dr.Cinzia Brunelli, with background and expertise in statistics, being a researcher who develops extensive work in the area of health care, particularly in cancer pain. Currently, she works in the Palliative Care Department in INT and jointly with the European Palliative Care Research Center, Department of Cancer Research and Molecular Medicine, Faculty of Medicine, Norwegian University of Science and Technology, Trondheim, Norway.

Some remarkable papers have been published by the Department (22–30), with important contributions to other ones (31,32), mainly in fields of expertise of its researchers, as cancer pain, delirium and palliative sedation.

2.7. CONTRIBUTION OF THE VOLUNTEERS OF THE ITALIAN LEAGUE AGAINST CANCER

It is not possible to describe the Palliative Care, Pain Therapy and Rehabilitation Unit of INT without talking about its volunteers. The volunteers of the Milanese section of the Italian League Against Cancer (*Lega Italiana per la Lota contro I tumori – LILT*) are a cornerstone in the assistance provided to cancer patients through all INT but with a notable role in the Palliative Care Unit. Their readiness to help in every setting, always with a tender word to give, not only to patients and families but also to the health professionals that everyday struggle to provide care within advanced illness, is remarkable. And they do it free of charge, in a true sense of citizenship and service to others. Their gestures are humble, discrete but extremely useful, and go much further than serving water and food in the waiting rooms and to inpatients. Some examples that I had the opportunity to testify during my stay in INT, include such diverse activities as: attendance to the cancer patients within the Institute, accompanying them for appointments and exams; supporting patients in hospice, just with their presence or registering patients' biographic notes, writing letters that they wish to send to loved ones, reading for them; giving support to families; visiting patients in their homes, as part of the Palliative Home Care Team, providing company, so important for patients who are not close to loved ones; helping doctors or nurses in bureaucratic and frequently exhausting tasks, easing jobs as organizing patient's databases, so useful to further evaluation of results; distributing quality of care and symptom evaluation' questionnaires to both outpatients and inpatients. For me, the work of the volunteers was impressive, making me realize that each one of them, with their knowledge, tastes and attributes, make a difference in the everyday experience in the Institute.

3. INTERNSHIP DESCRIPTION

In the following section I will try to describe how I've decided to organize the time I was given in the Institute, together with the host team, reviewing thoroughly the activities I've developed and in which I've been engaged, the population I've observed, the teams with who I've worked and how all this have allowed me to progressively meet the general goals which I've proposed, as well as to acquire the knowledge, skills and competences that I've projected for this internship.

During my 3 month' internship, it was given to me gradual self-sufficiency in execution of different tasks, in order to overcome initial goals. Thereby, I've observed in an autonomous, tutored way patients in different settings: outpatients, home patients, inpatients. This opportunity allowed me to develop skills that I'd never worked before, besides stimulating my mastery of the Italian language.

3.1. SCHEDULE

Having defined my goals and learning outcomes, I've developed with my internship supervisor and the whole team, an internship schedule for my 13 weeks, with 780 (31,2 ECTS) working hours, that I've followed scrupulously. This plan was organized based on a weekly schedule of 40 working hours, in the host institution, plus 20 hours a week dedicated to study, research homework, organize data and start the elaboration of the final report. The 520 hours spent working in the host institution were divided as follows:

- Outpatient clinics: 2 weeks (80 hours – 3,2 ECTS)
- Day Hospital: 2 weeks (80 hours – 3,2 ECTS)
- Inpatient consultation team: 2 weeks (80 hours – 3,2 ECTS)
- Hospice: 2 weeks (80 hours – 3,2 ECTS)
- Home care team: 2 weeks (80 hours – 3,2 ECTS)
- Research work: 3 weeks, (120 hours – 4,8 ECTS)

For the development of the final report, I've planned to dedicate 380 hours (15,2 ECTS) spread over 4 months. So, I planned to sum 46,4 ECTS.

In the end, I had to adjust the proposed schedule to everyday activities, so I could take the most time out of every day. Finally, this was how I organized my time in the Institute during the internship:

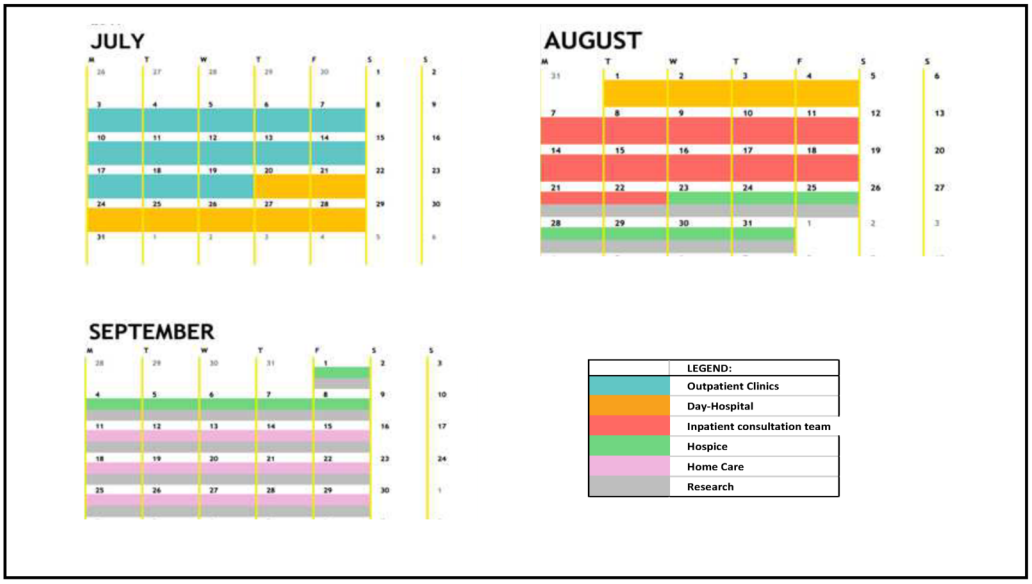

Figure 2 - Calendar with distribution of activities during the internship

3.2. OUTPATIENT CLINICS

I've followed the work in the Outpatient Clinics (OC) for two weeks, every day. The appointments were divided in first appointments, follow ups for symptom control and follow ups with therapeutics administration. Every day I had the chance to be part of all these appointments. The distribution of each type of appointment that I had the chance to follow can be seen in Figure 3. The motives justifying each visit were very variable, since they rely mainly on patients' needs.

Previously to each appointment, the patient would fill-in a pain and QoL questionnaire (Attachment 5). The pain questionnaire used the numeric rating scale (NRS) (33,34) to measure pain in the last week, in the last 24 hours, and presently. The pain NRS is a single 11-point numeric scale (NRS 11) with 0 representing no pain and 10

"the worst pain imaginable". Additionally, patients would fill a multi-dimensional quality of life questionnaire, the Therapy Impact Questionnaire (TIQ) (35), validated for cancer patients and developed in the beginning of the 1990s by a group of researchers from INT. It is a simple 36 questions questionnaire, with a 4-point Lickert scale, that evaluates 4 different dimensions: physical, that come from the disease or derive from treatments, functional capacity, psychological domain and social interaction. During my time in the OC I could follow questionnaire results of patients and acknowledge that more than half of them (55%) with 2 or more appointments at the OC or Day Hospital reported a pain intensity of 4 or less, reflecting a good overall pain control.

I've worked mainly with Dr. Francesca Ricchini, who completed her training as a medical oncologist and had integrated the Palliative Care team, due to her great interest and enthusiasm for this area. Since she has a strong background in medical oncologist, she is an expert in understanding the multiple side effects and disabilities that surgery, radiotherapy, chemotherapy and cancer targeted therapies can cause, in a short and long period, to cancer patients. I've also followed the work of Dr. Paola Bracchi and Dr. Fabio Formaglio.

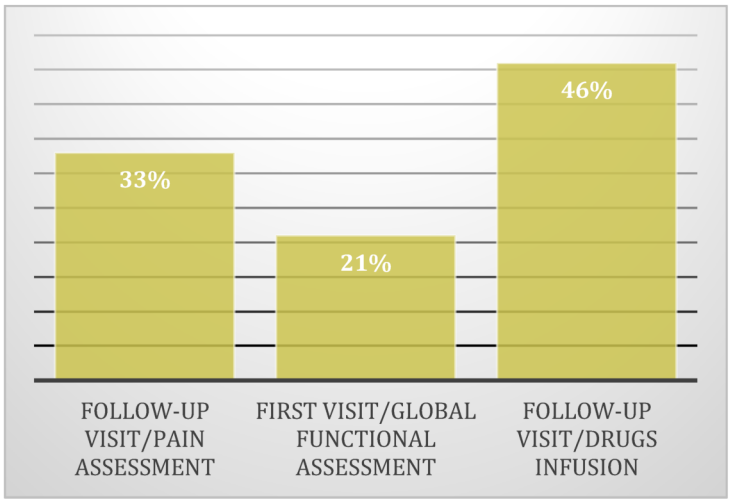

Figure 3- Distribution of types of appointments in the Outpatient Clinics

In the 2 weeks of work in the OC I've observed a total of 138 appointments and 130 patients, with a median age of 65 years old (IQ 25%-75% 57-74). The following Figure

4 and Figure 5 report demographic and clinical characteristics of these patients. The female population were more than half of the total population.

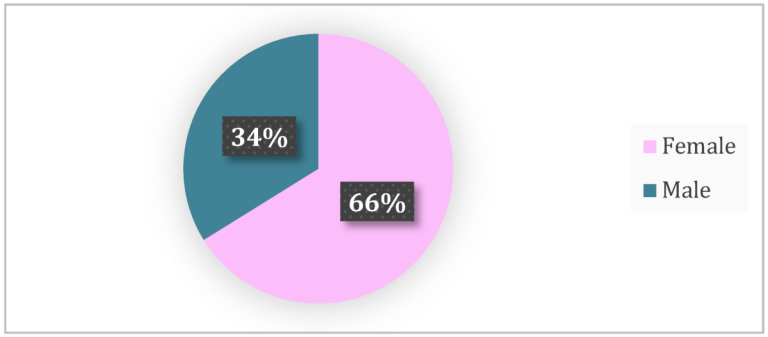

Figure 4- Sex distribution of patients observed in the Outpatient Clinics

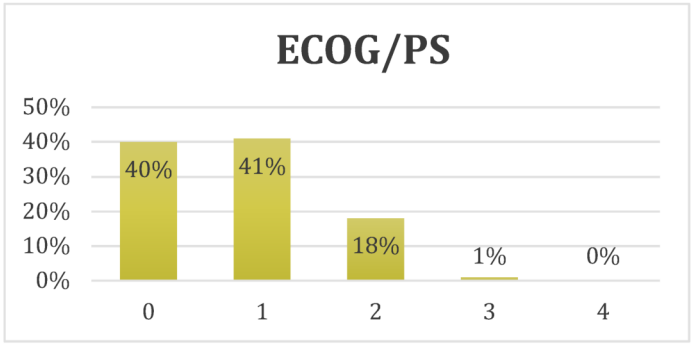

Figure 5 - Patient Distribution according to Eastern Cooperative Oncology Group (ECOG)/Performance Status (PS)

Probably in contrast with what would have been expected in a palliative care clinic, the great majority of patients followed presented a Eastern Cooperative Oncology Group (ECOG)/Performance Status (PS) of 0 or 1, corresponding to totally active patients capable of performing daily life activities without restriction (ECOG/PS 0) and patients restricted in physical strenuous activities but able to carry out lighter tasks (ECOG/PS 1). These data are according with the international guidelines which recommend referral of the cancer patient to a Palliative care team early in the course of the disease, while still able to enroll in daily life activities (14,36,37).

In what concerns the primary tumor location, the distribution can be seen in Figure 6. Around 90% of patients had stage IV cancer, being the most frequent places of metastases the bone (76%), lymph nodes (16%) and the liver (14%).

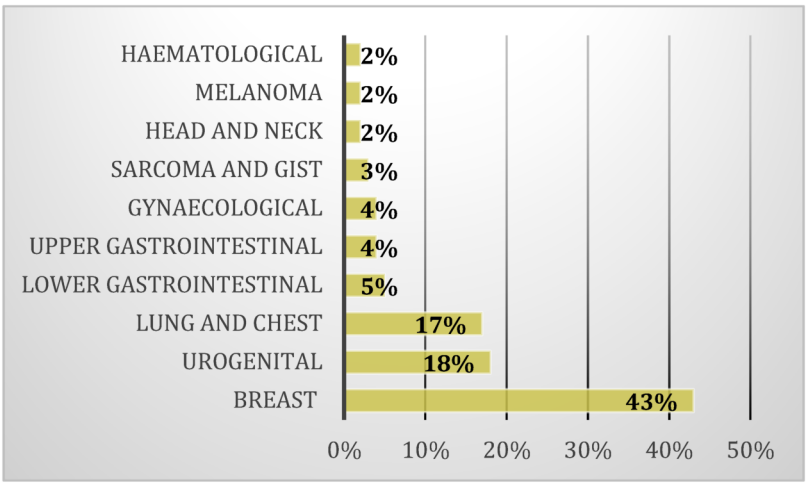

Figure 6 - Patient distribution according to primary tumor location (OC)

Of the 130 observed patients, 98 (75%) were under active oncologic treatment, with the distribution presented in Figure 7. This practice reflects also the recommendations of international guidelines, which state that comprehensive palliative care should be offered to patients with advanced cancer concurrent with active treatment (37).

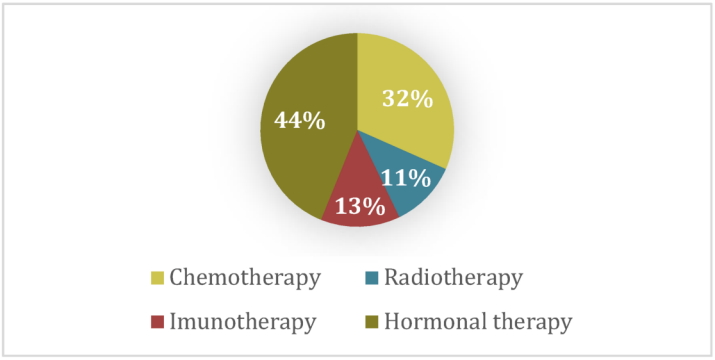

Figure 7 - Patient distribution according to active cancer treatment (OC)

A particular note for the first appointments I had the opportunity to enroll. In every first appointment, a global functional evaluation is carried out. As indicated before

(Figure 3), I've followed 29 first appointments, median age of 65 years (IQ 25%-75% 57-73), all with ECOG/PS under 2. Of these 29 patients, 26 had stage IV cancer, mainly with bone metastases (55%), and 15 were under active oncologic treatment (52%). On first appointment, median pain according to the filled pain questionnaire was 6.

In the Outpatient Clinics, pain is one of the biggest concerns and its careful assessment, approach and adequate treatment are of paramount importance. As stated by Caraceni et al (38) pain is the most persistent and incapacitating symptom of recurrent or metastatic cancer. Figure 8 shows the distribution of frequency of prescription of different opioid therapy. Fentanyl patches were the most frequent prescribed opioid, with most frequent indications being: moderate to severe pain; patients with unsuitable oral route, due mainly to emesis, dysphagia and/or diminished oral intake; patients unable to tolerate morphine due to persistent side effects; compromised renal function.

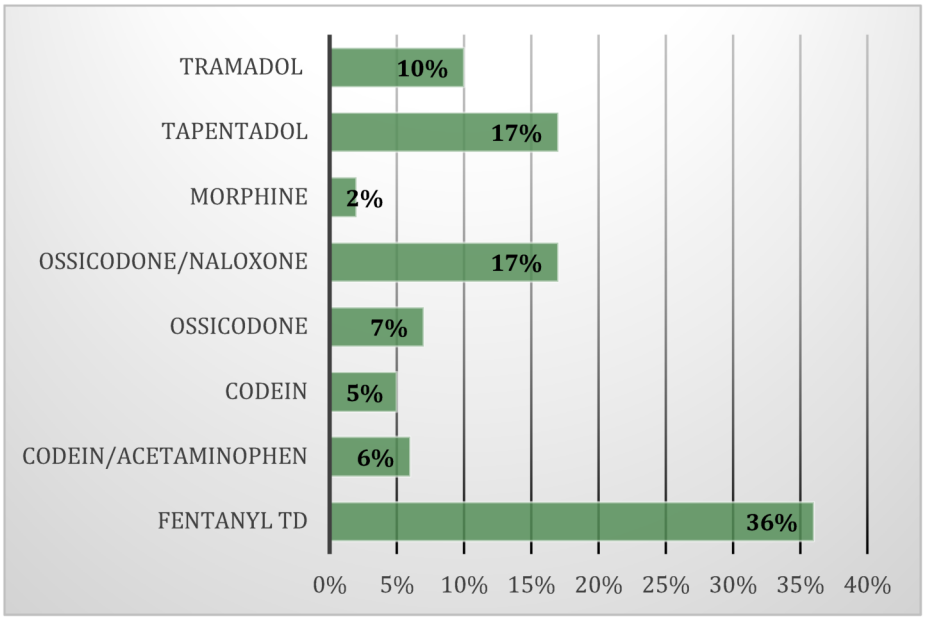

Figure 8 - Distribution according to type of fixed opioid analgesics (OC)

Since stage IV cancer with bone metastases accounted for around two-thirds of all cases, metastatic bone pain control was a frequent issue. When addressing metastatic bone pain, the immediate goal is to reduce pain at rest and during movement, and long

term aims focus on preventing pain progression and skeletal related events (SREs) (39). Together, these approaches have as final purpose to improve patients' QoL. An approach according to the analgesic ladder was taken, with the use of opioid and non-opioid analgesics, short course corticosteroids, referral to radiotherapy or to other interventional strategies, for the treatment of localized metastatic bone pain. International societies, as ESMO (40), recommend also the use of bone targeted agents (BTAs) (bisphosphonates and RANK ligand inhibitor denosumab) part of the therapeutics regimen for bone pain, but mainly for reducing SREs. Of the 84 patients with bone metastases that I've observed in the OC, 74 (88%) were under BTAs, 48 (65%) being Denosumab and 26 (35%) zoledronic acid. In fact, some phase III studies comparing zoledronic acid to denosumab have showed a bigger delay to onset of moderate/severe pain with the last one (41). These therapeutics were prescribed and administered in the OC, with periodical assessment of renal function as well as calcium and Vitamin D measurements and adequate supplementation when needed. Every patient, before starting BTAs, were referred to the stomatologist for dental assessment.

As stated by Hui *et al* (3), the OC is a hallmark of oncology-palliative care integration, for how they provide to cancer patients access to specialist palliative care early in the disease.

3.3. DAY HOSPITAL OF PALLIATIVE CARE

I've spent two and a half weeks in DH, following the work of Dr. Silvia LoDico. She introduced me to everyday activities in this department and gave me the possibility to understand how symptom control can only be managed effectively if approached in a multidimensional way. For this, the anamnesis was always a critical part of the assessment, and provided almost all the needed information, being at the same time therapeutic itself. Dr. LoDico gave me progressive autonomy to engage and lead appointments with patients, as well as to carry close examination. Thus, I've learned how

to adequately assess needs and goals, to adequately manage most common symptoms related with advanced cancer and to meet patient's desires and hopes.

Most of the patients I had the opportunity to meet in DH would come often to the OC, sometimes every day, so I got the opportunity to develop some bond with few of them. The patients enrolled for follow-up in DH were mostly patients with advanced disease and relevant symptom burden. I came to realize that this was an opportunity for many patients to better understand their disease, its impact, to clarify doubts and to define a treatment plan that would meet each patient's goals.

I've followed a total of 37 patients (Table 1), with median age of 73 (IQ 25%-75% 59-77), 62% female patients. Many of these patients would visit DH twice a week.

From the patients I had the opportunity to follow, main motives for admission and follow-up in DH were clinical monitoring and treatment infusions, due to poor control symptoms and high burden of disease, needing monitoring and treatment adjustment. I've separated pain control in a different motif of admission (Table 1), because these 4 patients were being followed exclusively for pain management, and they've represented significant learning moments for me, of how opioid titration, use of pain adjuvants, and control of irruptive pain, could be successfully managed in DH. When working in the DH, I've attended one abdominal catheter placement for drainage of ascites, and one thoracic catheter placement for pleural fluid drainage.

Table 1 - Clinical characteristics of patients observed in Day-Hospital

TOTAL NUMBER OF PATIENTS	37
Women, nr. (%)	23 (62%)
Age, years, median (IQ 25%-75%)	73 (59-77)
ECOG/PS	
0	2
1	21
2	13
3	1
FIRST VISITS	9
MAIN MOTIF OF ADMISSION	
Clinical Monitoring and treatment infusion	31
Pain Control	4
Invasive Procedures/Monitoring	2

Once more, most of patients in DH had stage IV disease (86%) mainly of the gastrointestinal tract (42%) (Figure 9), being the most common place of metastases the liver (Figure 10). Half of patients (51%) were under active treatment with chemotherapy.

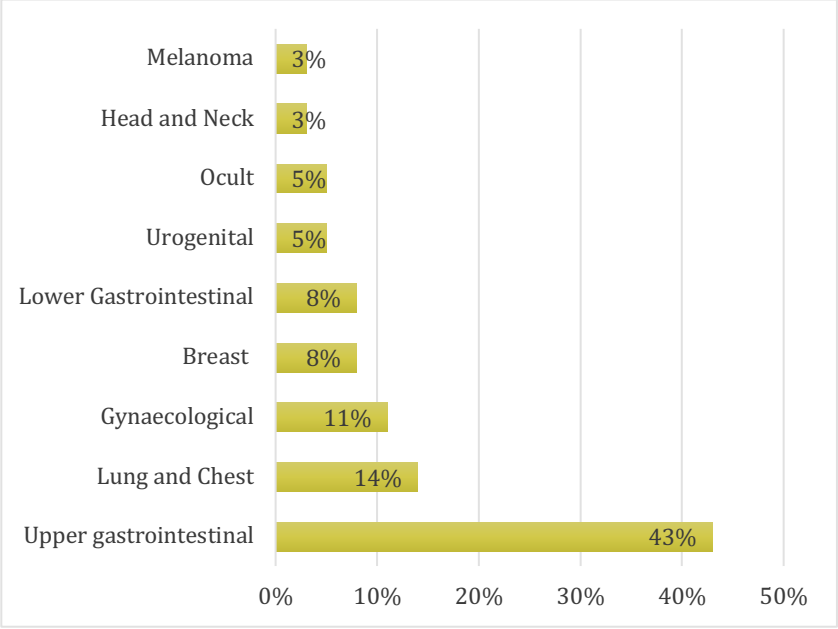

Figure 9 - Distribution of patients in Day Hospital by primary tumor location

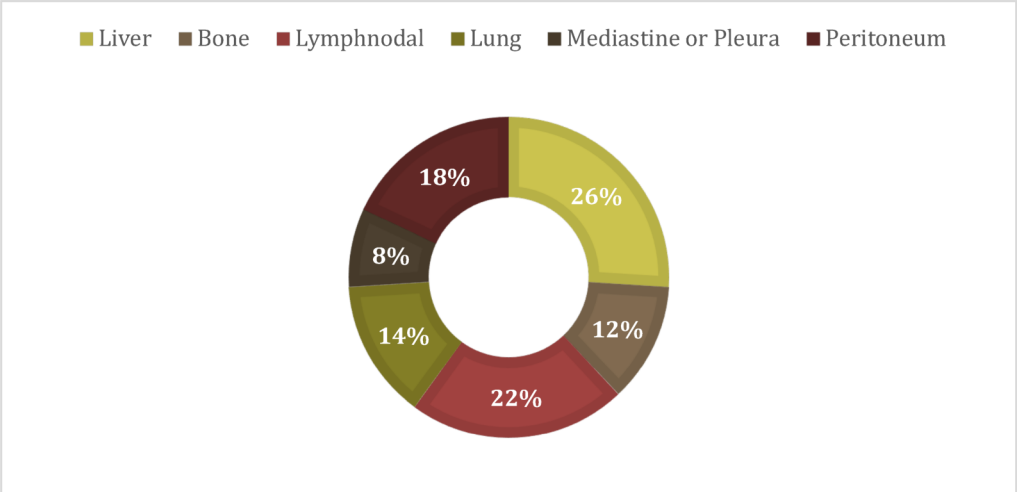

Figure 10 – Distribution of patients according to metastases location (DH)

3.4. INPATIENT CONSULTATION TEAM

I've followed the inpatient consultation team throughout two and a half weeks. During this time, I've observed 31 patients, although most times, the same patient was assessed almost daily, depending on the situation. An average of 6 patients were evaluated daily. As mentioned earlier, main request' motives for inpatient assessment were uncontrolled pain (81%), other non-controlled symptoms (dyspnea, constipation, emesis, hiccups) (10%), being the remaining motives patients in end of life, mainly when in need for palliative sedation, not being possible to transfer them to hospice due to lack of availability. It is relevant to state, however, that besides this motives, multiple issues frequently were addressed and managed by the inpatient team.

The median age of the observed patients was 64 years old (IQ 25%-75% 46-70), 18 patients were females (Table 2) and the most frequent primary cancer site was sarcoma (Figure 11) with 65% patients having stage IV disease.

Table 2 - Data regarding patients observed with the Inpatient Consultation Team

TOTAL NUMBER OF PATIENTS	31
Women, nr. (%)	18 (58%)
Age, years, median (IQ 25%-75%)	64 (46-70)
ECOG/PS	
0	7
1	8
2	10
3	5
4	1
FIRST VISITS	9
VISITED DEPARTMENTS	
Mesenchymal and rare tumors and Melanoma	9
Ear, Nose and throat	1
Radiotherapy	1
Hematology	1
Medical Oncology	8
Gynecology	1
Urology	1
Colorectal Surgery	1
Thoracic Surgery	6
Hepato-Biliary-Pancreatic	1

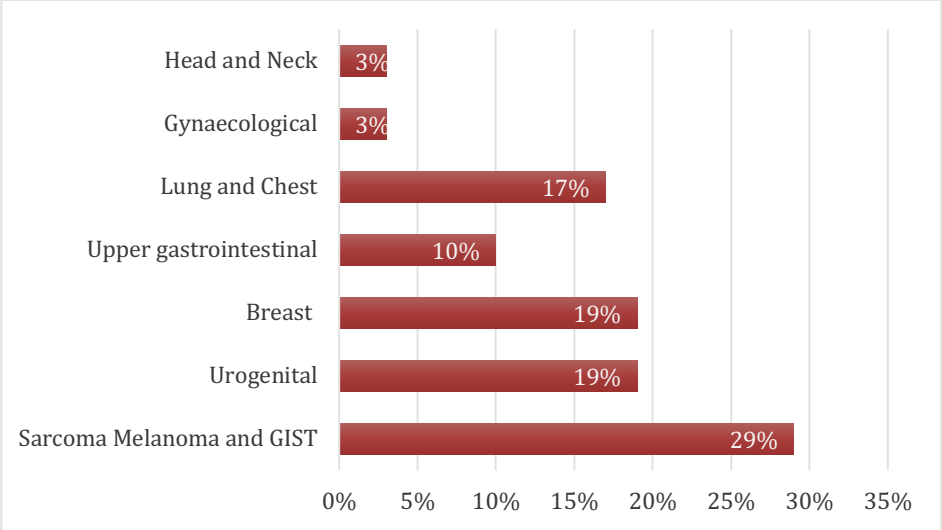

Figure 11 - Patient distribution according to primary tumor location (Inpatient Team)

From the 31 patients, 2 died during the observation period, 4 were transferred to hospice due to progressive disease with high symptom burden and 4 were discharged with assurance of palliative home care team support.

It is of particular importance to underline that, previously to each transference of an inpatient to the home or hospice setting, a family conference was undertaken, in order to clarify the current clinical situation, discuss prognosis, answer to doubts, assess needs or specific support to relatives, their coping with the illness and related symptoms.

3.5. HOSPICE

Dr. Cinzia Martini is the Hospice's medical coordinator, and her daily tireless and systematic work contribute to the success of the provided care in this setting. I've worked with Doctor Martini during my 3 weeks of stay in this sector.

The criteria to be admitted in Hospice are several, but some requirements are needed. For example, patients should not be under any active cancer treatment, and be in need for specialized care.

I've divided the main motives for recovery in Hospice as shown in Figure 12, since these were the main issues that motivated the admission in this PC setting.

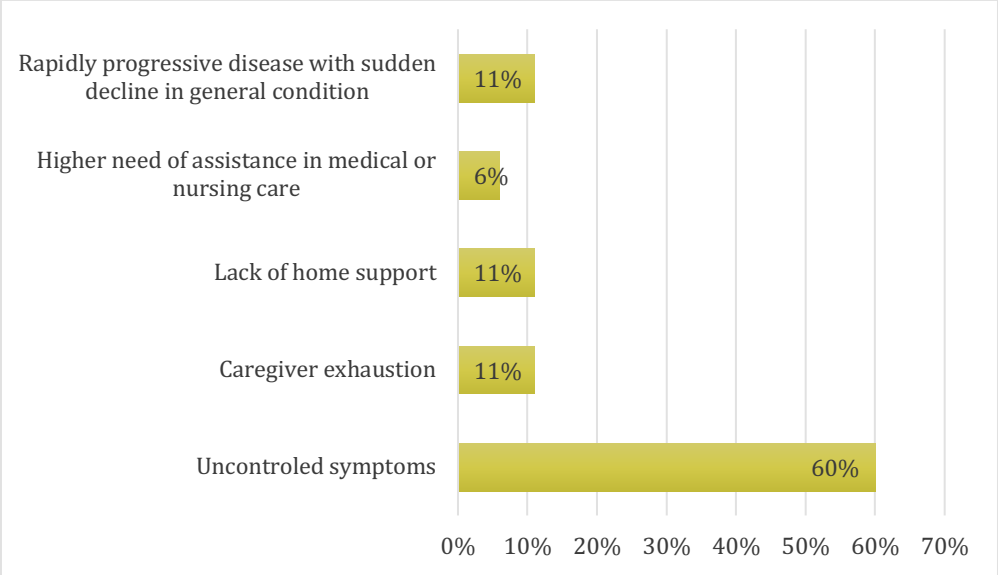

Figure 12 - Motives for admission in Hospice

Often, more than one of these motives was present. High symptom burden of difficult ambulatory management was the main issue to prompt admission in Hospice, but the lack of home support or the rapidly progression of cancer which would precipitate worsening symptoms were frequent scenarios.

As can be seen in Table 3, patients were most often referred from the day hospital of Palliative Care or from another department of INT, through the evaluation of the inpatient consultation team. Of note that the most common department from where patients were referred was the Medical Oncology Department (89%) .

During my period in Hospice, I've observed a total of 35 different patients (Table 3), with median age of 70 years (IQ 25%-75% 62-77), 46% female. The average time of recovery in Hospice was of 8 days (SD 10).

Table 3 - Data regarding patients admitted in Hospice

TOTAL NUMBER OF PATIENTS	35
Women, nr. (%)	16 (46%)
Age, years, median (IQ 25%-75%)	70 (62-77)
ECOG/PS	
0	0
1	1
2	6
3	16
4	12
NEW ADMISSIONS	17
ORIGIN	
Day Hospital of Palliative Care	10
Palliative Home Care Team	7
Another INT department	9
Another Hospice	5
Emergency Department	4

Almost all patients (89%) had stage IV cancer and most commonly lung or bone metastases, being the most frequent origin of the primary tumor the gastrointestinal tract (Figure 13). As confirmed by the ECOG/PS of the admitted patients (80% with PS 3 or 4) these were predominantly patients with severely impaired functionality, as expected.

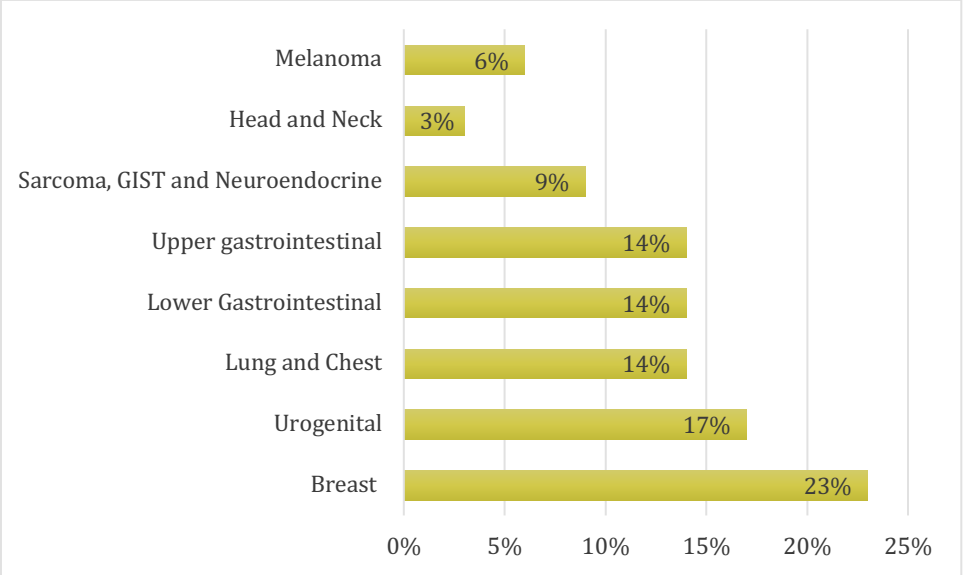

Figure 13 - Patient Distribution according to primary tumor location (Hospice)

When analyzing symptom burden, the most frequent poorly controlled symptoms were, in order of frequency: dyspnea, nausea, vomiting (more often due to malignant bowel obstruction), fatigue, pain and impaired oral intake. Management of these symptoms was regularly complex, and made in a multidisciplinary and staged way. A symptom assessment with the help of the ESAS form (Edmonton Symptom Assessment Scale) (Attachment 2) was used to help record a regular monitoring of different symptoms, and Palliative Performance Scale (PPS) to evaluate functionality and dependency (Attachment 6). Additionally, on admission, a cancer specific palliative prognostic scale was usually applied, as the Prognosis in Palliative Care Study (PiPs) (42–44), the Palliative Performance Index (PPI) (45) or the Palliative Prognostic Score (PaP) (46). Generally, these prognosticators encompass information regarding the diagnosis, symptoms, general health, blood results and the clinician's estimate (Attachment 7, Attachment 8). This data are extremely helpful in making critical decisions and, together with communication with the patient and family (47), provide better prognostication then the assessment of the most commonly used way to define prognosis for oncologists, the ECOG/PS. This last way of assessing patient's condition and deciding for further approaches can be extremely discordant, and therefore, if taken alone, can be a subjective criteria (48).

Having in consideration the results provided by the above-mentioned tools, and after a careful assessment of patients and their caregivers needs, wishes and preferences as well as patient's life expectancy, an advanced care plan was designed, setting goals and priorities. In hospice, needs were met in a structured way, applying Maslow's hierarchy of needs, which allowed a comprehensive approach in order to achieve, not only symptom control and patient's comfort, but also to allow the patient to fulfill further domains, like engaging in activities that give him/her pleasure. For example, it would be extremely difficult to talk with a patient about a trip he would like to make in his last month of life, if he is suffering with severe pain.

In Hospice, I've had the opportunity to witness how different fields of care come together in the promotion of the patient and their families' well-being, whose work is based on needs, not prognosis, regardless of the goal being discharge, or the provision of comfort in the end of life. A multidimensional and individualized approach was the rule and teamwork a reality. Every morning a quick briefing was made with nurses, to communicate complications from the night before. Then, a round was made to check on every room and then patients were divided by the different members of the medical team. During my time in Hospice, besides Dr. Martini, I've worked with a colleague in training from Anesthesiology, Dr. Riccardo Di Rosso. In the first days I accompanied Dr. Martini and Dr. Di Rosso in their activities, but soon I started being responsible for some patients. Every note and therapeutic was recorded informatically. Under my charge I had also admissions and discharges. Our activities were extremely variable, depending on the patient. For example, I've participated in a central venous catheterization, for a patient in need for intravenous antibiotics without peripheral venous access.

From the 35 patients I've followed in Hospice, 27 (67,6%) died during my stay. Uncontrolled and intolerable dyspnea and delirium were the two most frequent reasons to undergo palliative sedation in Hospice, performed in 20% of the patients who died. This procedure was undertaken in a monitored and strict way. The patient, with an advanced and irreversible disease, would present with an intolerable and refractory symptom, meaning that it was not controlled with the available medical procedures. Sedation was started usually in an intermittent way, with the main goal being the least

sedation for the maximum control of symptoms. This refers to situations where urgent sedation was not the case, as would be the case for example of massive bleeding. Sedation was monitored using the Richmond Agitation Sedation Scale (RASS) (Attachment 9) and symptom control through clinical observation. Assessments of consciousness, motor activity or agitation were routinely made. The most frequently used drug for sedation was Midazolam.

Every member of the hospice provided holistic and targeted care. The morning period was usually the time for the medical visits, changes in medical therapeutics and execution of procedures by both medical and nursing teams. The afternoon was reserved for the work of physiotherapists, shiatzu therapist, phycologist. The patient and the caregivers received routinely care and assistance, in order to cope with the disease and its boundaries, as well as with the end of life. Short time goals were continuously reviewed and adjusted, and priority was given to life story and legacy activities. Nevertheless, some specific cases marked me, maybe for how they challenged palliative care in one of its most fundamental goals: the relieve of suffering. As an example, I mention a 56-year-old woman with stage IV breast cancer, transferred from the Medical Oncology Department. Her cancer had spread to the lymph nodes, bones, lungs, liver and now, arising as a right-side hemiparesis, metastasis in the brain. This woman was severely anxious, suffering with back pain, breathless and not able to take care of herself. In hospice, we could help her treating some sources of her “total pain”. But her existential distress was much more challenging. Some dimensions of human suffering can be extremely demanding and sometimes even frustrating for health care providers. The importance of teamwork and shared decisions regarding complex end-of-life situations was one of the biggest lessons I’ve learned in this setting.

During my work in Hospice, 3 patients were discharged, all home and with support of the Palliative Home Care Team.

3.6. PALLIATIVE HOME CARE TEAM

For 3 weeks, I've followed the work of the Palliative Home Care Team, side by side with Dr. Tiziana Campa, a true expert in what concerns needs and symptom' management of cancer patients with advanced disease in the home setting. Dr. Tiziana taught me how the environment that surrounds the patient is key to his/her wellbeing, and so being able to keep the patient comfortable in a familiar space is both challenging and reassuring.

Every day we would visit patients according with a previously organized agenda, that would be adjusted depending on patients' needs and evolution. I've followed a total of 16 patients, median age 78 (IQ 25%-75% 74-83). As can be seen in Table 4, most patients had advanced disability as evaluated by ECOG/PS.

Table 4 - Data regarding patients observed with the Home Care Team

TOTAL NUMBER OF PATIENTS	16
Women, nr. (%)	8 (50%)
Age, years, median (IQ 25%-75%)	78 (74-83)
ECOG/PS	
0	0
1	3
2	4
3	5
4	4
NEW ADMISSIONS	7
ORIGIN	
Day Hospital of Palliative Care	9
Hospice	2
Outpatient Consultation Team	2
Medical Oncology Department	2
Another Hospital	1

During my work with this team, 7 new patients were enrolled in the Home Care Team, most referred from the Day Hospital of Palliative Care. Main motives for admission were symptom control (44%), advanced disability due to progressive disease (44%) and rapidly

progressive illness expected to trigger intense burden of disease (56%), being that more than one motif could be present for the same patient. Every patient had metastatic (75%) or advanced disease (25%), with high variability in primary cancer, being breast cancer the most frequent. Most common places of metastases were the lung and pleura (44%), followed by bone (25%). The most uncontrolled symptoms, reported in Figure 14 were associated with location of primary cancer and metastasis. Fatigue and anorexia/cachexia were the most frequent, followed by delirium, pain and dyspnea. More than one symptom was often present, and in Figure 14 are only reported the most remarkable and demanding in what concerns symptom control.

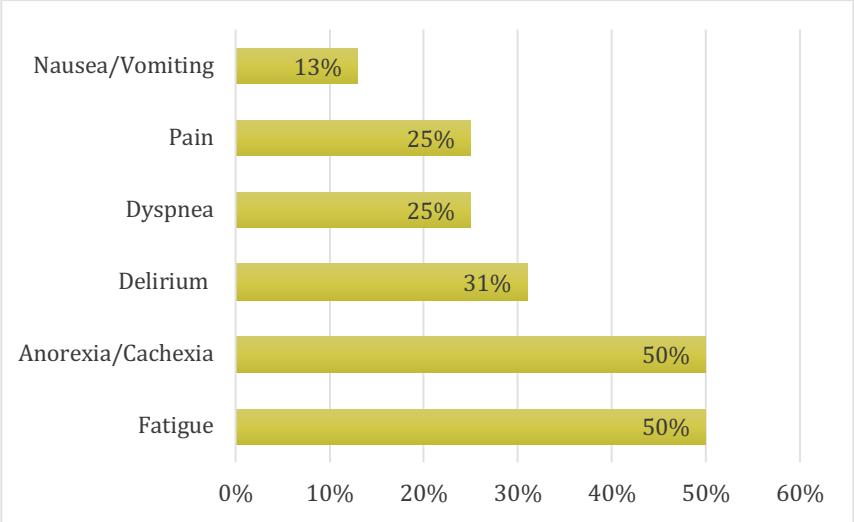

Figure 14 - Main symptoms assessed in Home Care patients

Our average number of visits per week to each patient was 2, and average time of follow-up was 33 days. From the 16 patients that I've observed, 5 died during this period. Palliative sedation was performed in 3 cases, 2 for refractory dyspnea and one due to intractable hyperactive delirium. Midazolam was the drug of choice for performing palliative sedation. One patient died in the emergency department.

I've realized during this part of the internship how Palliative Home Care assistance is not only crucial for patient's comfort, but also for families and other relatives, not just as a help and guide for symptom management, but also as a support in the last days of life, and after, in dealing with grief. I would also emphasize how important the assistance

provided by the Palliative Home Care Team is essential to clarify treatment goals as well as to assess and support coping needs.

3.7. MULTIDISCIPLINARY MEETINGS

Two of the hallmarks of the Palliative Care Unit are its multidisciplinarity and the importance given to team work. The weekly meetings that take place in the Unit are a portrait of this, being excellent opportunities to exchange knowledge, discuss challenging cases, share doubts regarding certain patients, in a truly educational way.

Each Tuesday takes place the Hospice meeting, and each Friday the Palliative Home Care Team meeting. Each meeting counts with the attendance of the entire health team who works in that section, including volunteers assigned to each setting. The team discusses each patient and each team member is welcomed to contribute to the reassessment of each patient' advanced care plan. The provision of comfort and meeting needs are the priorities of the discussions that take place weekly. Debriefings are also performed, whenever needed, mainly after occurrences that would be desired to have a different outcome.

The Hospice team gathers weekly to update advanced care planning set up for each patient, to define strategies, discuss concerns, share expectations presumed from communication with the patient.

The Home Care Team gathers also weekly to discuss advanced care planning for each patient, redefine intensity of care, according to events occurred in the previous week, to share feedback concerning each patient, family and/or caregivers, to list unsolved problems and needs to be tackled.

The Unit also organizes weekly Journal Clubs, but since my internship was during the holiday season (July to September) I didn't have the opportunity to be part of any.

Every of these meetings were extremely productive and enriching and the contribution of every intervenient was important to structure multidimensional approaches, individualized for each patient.

3.8. RESEARCH PROJECT

During 3 weeks of my internship, I've worked in partial time in research in the Palliative Care Unit. My main goals during this period were to get familiar with the methodology and development of a research project and to be actively involved in such. This was undoubtedly an important time of learning in what pertains the design of a research study, which is set from a question to which an answer is to be found. With the help of Dr. Alessandra Raimondi and the supervision and extensive contribution of Dr. Brunelli and Dr. Caraceni, a research project was developed in the field of palliative sedation, conducted by this Department as a multicenter observational longitudinal study. The study intended mainly to compare palliative sedation in Hospice and Home settings, to understand patients' clinical characteristics, decision making processes in what concerned palliative sedation techniques, practical aspects, indication, used methodology and monitoring. Data were already collected, from several Palliative Care Units in Italy. Dr. Cinzia Brunelli analyzed data and reported the results, as we developed bibliography research, elaborated both introduction and conclusions and developed the final paper. The work was laborious but extremely rewarding, being published in March 2018 in the Journal of Pain and Symptom Management, entitled: Palliative Sedation In Terminal Cancer Patients Admitted To Hospice Or Home Care Programs: Does The Setting Matter? Results From A National Multicentre Observational Study (APPENDIX 1).

4. FINAL REMARKS

I could describe exhaustively how the experience of PC in INT made me achieve my proposed goals, how every experience in each section contributed for this, but I think the best way of demonstrating the type of experience I've lived, and how I've learned, is by telling a story. This story I've retained in my mind, for it is an example of suffer, of extraordinary courage, of devotion, but most of all, it is the story of extraordinary human beings.

I will describe this man, let's call him Antonio. In the summer of 2017, he arrived to the Outpatient Clinics of palliative care, hands with his wife, sent by his medical oncology assistant. He had just been diagnosed with stage IV pancreatic cancer, with liver and lung metastases. He was a singer. He lived in an old apartment, big windows and a little balcony, with his wife and his 19-year-old son. When he came to the PC Clinics, he was exhausted. He was also in pain, and for this, he couldn't rest at night. In the following 3 weeks, he came to the Day Hospital twice a week, so we could control his pain and find the right treatment for him. Despite our success in controlling his symptoms, the disease was progressing quickly, and he was becoming more asthenic, sarcopenic and dependent. After 3 weeks, he was coming to the DH in a wheelchair and could only be comfortable when lying down. At this point we've decided to pass the case to the Home Care Team. At first, his wife was very resistant about this decision. She couldn't stop feeling we were giving up. After long conversations and clarifications, she agreed with us, and decided to be his main caregiver. She learned how to administer several subcutaneous drugs, with the help of the HC team nurses, that provided also the kit with several medicines that could be useful. She learned when and how she should administer each one of them, and that she could always call and ask for help. The home care doctor responsible for him, Doctor Paola Bracchi, visited him twice a week in the first weeks. She adjusted the opioid route of administration to a patch when Antonio started being very reluctant to take meals, and after 30 days, she started visiting this family almost daily, since the patient was starting to have dyspnea. The wife was now very anxious, as she felt she couldn't

manage this symptom properly and therefore not able to have his husband comfortable at home anymore. Wife and son confessed that they were also afraid of watching him dying, because they felt they weren't prepared to assist him at that point. Antonio had now some periods of clarity but often he was sleeping. His breathing was progressively harder. That's when the team and the family decided that the best option would be to move him to hospice. With the help of the whole team, wife and son were always present and supported. With symptom control, they could feel calmer and more comfortable being around him. Antonio spent 17 days in hospice before dying, peacefully, surrounded by his wife and son. Some weeks after Antonio's death, they both visited the hospice, to thank the whole team and leave some homemade cookies. They sat in the living room for some time, in silence, except for the twittering of birds. For them, that place was a sanctuary, a place they felt was full of life and hope. They were really brave, and we all told them how we admired their strength and devotion. They were at peace. Nothing could be most rewarding. Thanks to this amazingly well-designed structure, this family, whose path they didn't choose, was allowed to cross it calmly and devoted to what really mattered, until the end.

5. CONCLUSIONS

According to the Oxford Dictionary, a synecdoche is a figure of speech in which the part is made to represent the whole. In Medicine, we often tend to appeal to this literary device, probably influenced by our training, by our systemized mentality, and by the so-called organ-site approach (49). However, the only way to properly address and relieve our patients' suffering, is by considering the totality of the person, reminding once more the pain's global concept of Dame Cicely Saunders (5). As stated by an oncologist colleague "Holistic care is a challenge, it is demanding, tiring and difficult, but it is the only way to practice oncology with dignity and success"(49).

This approach demands us to be capable of recognizing the other's vulnerability, leading to a compassionate presence towards the person in need (50). This genuine attitude avails from the understanding that, often, a disease emerges in a person's life, little by little, and suddenly takes the leading figure. For the patient, the universe turns into a low ceiling, a sky without stars and without the infinite. The disease can be profoundly claustrophobic and its voice monotonous and terrifying (51). But who prepared us to deal with suffering, with vulnerability, and even more, with mortality? Leo Tolstoi's Ivan Ilitch (52) is a personification of suffering and the loneliness of dying, of the human's inability to deal with the end of life, and it is therefore an appeal to ethics, to compassion, to the respect for human dignity. Also, Atul Gawande wisely reminds us that death is not failure. Death is normal, and it is the natural order of life (53). But our modern society has insisted on disagreeing, as since the end of the eighteenth-century death started being seen by the medical teams as sign of defeat, and so to be avoided at all cost. Every patient was treated until the last heartbeat, without a clear discussion about goals of care. Death became hospitalized, dissected to little steps (54), and the limitations of medicine were forgotten, as that all care is not good care, sometimes it is even harmful and burdensome for the patient, the relatives and the staff. Palliative Medicine has emerged to host the person in suffer, and more than talking about death and dying, to focus on having the best quality of life possible (55).

My last 2 years have been absorbed in reading and studying about palliative care. For this, the palliative care masters helped me tremendously. But I lack practical training. And so, my choice of doing an internship in the Palliative Care, Pain Therapy and Rehabilitation Department of Istituto Nazionale dei Tumori in Milan, besides my knowledge of the Italian language, was driven by the will to work in a high-level palliative care centre, with the opportunity to develop research work of high quality and high standard and with teams that work at all levels of assistance and in an integrated way. These teams also have a vast experience working with cancer patients, in a country with a social, cultural and economic ground very close to the one in Portugal, where the main difficulties and challenges probably converge. But the choice to internship at this Unit was also driven by the person that leads it. Dr. Augusto Caraceni is a worldwide renowned name in the field of palliative care and pain therapy, who has been devoting his work to creating excellency in the palliative care field, both nationally and internationally. As stated in the webpage of the Institute "His clinical and research experience include the palliative treatment of advanced cancer, neurological complications of cancer, cancer pain classification assessment and treatment with particular attention to opioid analgesics, and symptom control with a special interest in delirium. He is the author of more than 160 scientific articles in indexed journals, on palliative care, cancer pain and cancer care (…)". Professor Caraceni is a cornerstone that makes this centre a reference in palliative care, offering a complete and holistic assistance to the patient, with a strong commitment and contribution in research activity, innovative therapies, and education.

The Palliative Care internship in INT represented for me an enormous opportunity of discovery and resilience. But a great challenge brought by this experience was to understand how I could extrapolate everything I've learned to my country, to my hospital and to my daily reality. Not having a clear answer yet, there are some aspects I would like to emphasize, that have made an impression. In first place, the role of the volunteers: they are crucial and make a tremendous difference in the daily work of the PC Unit. In second place, I highlight the exemplary organization system of the PC Unit. Every section work in straight coordination, allowing an easy referral of each patient to the most

appropriate type of care. The communication between each member of the PC team was constant, clear and precise, and the work always made towards the patient's benefit. At last, I underline the teamwork of all the people with who I've worked with. Often the working schedule left little time to educational or research activities. Nevertheless, and so that this work was not jeopardized, the team would readjust whenever one team element was under tight deadlines or in need to attend to courses or a congress or finish papers. This working model of true teamwork and support have inspired me to keep and foster a similar practice in my daily activity.

In the end of this internship, the balance couldn't be more positive: I considered fulfilled the general and specific goals that I've set to this period, namely in what concerns a multidisciplinary approach to the palliative cancer patient, combining knowledge and technique, to the sensibility of recognizing the person in suffering, and to adequately address it. The ascending acquisition of independence, always with orientation, have allowed me to gain the necessary autonomy to gain confidence in the practice of Palliative Care, as well as management and decision skills that have globally enriched my clinical ability.

This 3 months experience have largely exceeded my initial expectations. I've learned so much, but mostly how an integrated model of palliative care can, indeed, make a tremendous difference in the quality of life and in the survival of the person living with cancer, as well as considerably reduce health associated costs.

I finish this report thankful for the past and sighting the future. My wish is to become a palliative oncologist, and while the Master in Palliative Care established solid ground of knowledge, skills and competences that will guide me in my future practice, giving me indispensable tools, this internship has taught me how to use them on behalf of the others. From here, I believe that my dedication, passion and teamwork will make a difference. Ultimately, my wish is to be able to give my contribution to the delivery of top quality palliative care in my country. My optimism and confidence come from the certainty of the words of Lewis Carroll *"One of the deep secrets of life is that all that is really worth doing is what we do for others*".

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7. ATTACHMENTS

ATTACHMENT 1

SCHEDA RACCOLTA DATI: MORSE FALL SCALE

Cognome e nome malato _____

Anno di nascita |__|__|__|__| **Sesso** F ☐ M ☐

Rilevatore _____

DATA _____

|__| **Primo accesso** |__| rivalutazione *

* Indicare le variazioni cliniche

Alterazione stato coscienza |__|
Alterazione parametri |__|
Alterazione mobilità |__|
Variazioni terapeutiche importanti e/o effetti collaterali terapia |__|
Comparsa dolore |__|
Altro |__| _____

SCALA MORSE		
Indicatori	**Punteggio**	
Anamnesi di cadute	**SI**	**NO**
Se il paziente cade per la prima volta durante l'assistenza in corso o è caduto nei tre mesi precedenti all'ammissione	25 **O**	0 **O**
Compresenza di diagnosi primaria e secondaria		
Se il paziente ha più di una diagnosi medica (es: diabete e neoplasia)	15 **O**	0 **O**
Mobilità		
Se il paziente cammina senza ausili	0 **O**	
Se il paziente, assistito da un infermiere, usa la sedia a rotelle	0 **O**	
Se il paziente è immobilizzato a letto	0 **O**	
Se il paziente usa le stampelle, il bastone o il deambulatore	15 **O**	
Se il paziente cammina senza ausili, aggrappandosi agli arredi	30 **O**	
Terapia Endovenosa		
Se il paziente ha infusioni endovenose	20 **O**	0 **O**
Andatura		
Se normale	0 **O**	
Se debole	10 **O**	
Se pericolosa	20 **O**	
Stato Mentale		
Se il paziente è orientato nel tempo e nello spazio	0 **O**	
Se il paziente è disorientato	15 **O**	
Totale		

Punteggio:
0-24 = (paziente con basso rischio)
25-50 = (paziente a rischio di caduta)
≥51= (paziente a massimo rischio)

ATTACHMENT 2

ESAS

La preghiamo di rispondere a tutte le domande del questionario apponendo una crocetta sul numero che meglio descrive la sua situazione in questo momento (esempio: X)

DOLORE	*PER NIENTE*	0 1 2 3 4 5 6 7 8 9 10	*IL PEGGIOR DOLORE POSSIBILE*
STANCHEZZA	*PER NIENTE*	0 1 2 3 4 5 6 7 8 9 10	*LA PEGGIOR STANCHEZZA POSSIBILE*
NAUSEA	*PER NIENTE*	0 1 2 3 4 5 6 7 8 9 10	*LA PEGGIOR NAUSEA POSSIBILE*
DEPRESSIONE	*PER NIENTE*	0 1 2 3 4 5 6 7 8 9 10	*LA PEGGGIOR DEPRESSIONE POSSIBILE*
ANSIA	*PER NIENTE*	0 1 2 3 4 5 6 7 8 9 10	*LA PEGGIOR ANSIA POSSIBILE*
SONNOLENZA	*PER NIENTE*	0 1 2 3 4 5 6 7 8 9 10	*LA PEGGIOR SONNOLENZA POSSIBILE*
MANCANZA DI APPETITO	*PER NIENTE*	0 1 2 3 4 5 6 7 8 9 10	*LA PEGGIORE INNAPETENZA POSSIBILE*
MALESSERE	*PER NIENTE*	0 1 2 3 4 5 6 7 8 9 10	*IL PEGGIOR MALESSERE POSSIBILE*
DIFFICOLTA' A RESPIRARE	*PER NIENTE*	0 1 2 3 4 5 6 7 8 9 10	*LA PEGGIORE DIFFICOLTA'A RESPIRARE POSSIBILE*
ALTRO	*PER NIENTE*	0 1 2 3 4 5 6 7 8 9 10	*IL PEGGIOR POSSIBILE*

COGNOME E NOME DEL PAZIENTE _____

DATA DI COMPILAZIONE _____

COMPILATO DA ME STESSO O DA ME DETTATO A QUALCUNO [ ]

COMPILATO DA UN MEDICO O UN INFERMIERE [ ]

COMPILATO DA UN FAMILIARE [ ]

MOTIVO DELLA COMPILAZIONE DA PARTE DEL MEDICO, DELL'INFERMIERE O DEL FAMILIARE:

- *RIFIUTO DEL PAZIENTE*
- *PROBLEMI FISICI/COGNITIVI GRAVI DEL PAZIENTE*
- *PROBLEMI ORGANIZZATIVI*
- *ALTRO MOTIVO* _____

ATTACHMENT 3

Nome: _____ Cognome:_____ Data consegna:___/___/____

I farmaci contenuti sono da utilizzare solo ed esclusivamente dopo aver consultato il medico

FARMACO	QUANTITA'	A COSA SERVE	COME SOMMINISTRARE
BUSCOPAN FIALE	1 CONF	DOLORI ADDOMINALI, RIDUCE LE SECREZIONI (RANTOLO)	Iniezione sottocutanea
MIDAZOLAM FIALE DA 5 MG	1 CONF	SEDATIVO	Iniezione sottocutanea
LASIX/FUROSEMIDE FIALE	1 CONF	DIURETICO	Iniezione sottocutanea o endovenosa
MORFINA CLORIDRATO FIALE DA 10 MG	1 CONF	ANTIDOLORIFICO, DIFFICOLTA' A RESPIRARE	Iniezione sottocutanea
PLASIL/METOCLOPRAMIDE FIALE	1 CONF	ANTINAUSEA, ANTIVOMITO	Iniezione sottocutanea o endovenosa
SERENASE /ALOPERIDOLO FIALE DA 2 MG	1 CONF	CONTROLLA AGITAZIONE ED ALLUCINAZIONI	Iniezione sottocutanea
SOLDESAM/DESAMETASONE FIALE DA 4 MG	1 CONF	ANTINFIAMMATORIO	Iniezione sottocutanea o endovenosa
TORADOL/KETOROLAC FIALE DA 30 MG	1 CONF	ANTIDOLORIFICO	Iniezione sottocutanea
UGUROL/ACIDO TRANEXANICO	1 CONF	ANTIEMORRAGICO	Iniezione sottocutanea, uso locale, assunzione per bocca
ORAMORPH FIALOIDI DA 10 MG	1 CONF	ANTIDOLORIFICO, DIFFICOLTA' A RESPIRARE	Assunzione per bocca
LEVOXACIN/LEVOFLOXACINA COMPRESSE DA 500 MG	1 CONF	ANTIBIOTICO	Assunzione per bocca
XANAX/ALPRAZOLAM/FRONTAL GOCCE	1 CONF	SEDATIVO	Assunzione per bocca
TAVOR COMPRESSE ORODISPERSIBILI DA 1 MG (?)	1 CONF	SEDATIVO,FAVORISCE IL SONNO	Assunzione per bocca

CONTIENE INOLTRE:

ATTACHMENT 4

FONDAZIONE IRCCS ISTITUTO NAZIONALE DEI TUMORI	CARTELLA ASSISTENZA DOMICILIARE SPECIALISTICA CURE PALLIATIVE	ALL-PRO-P-06

CARTELLA CLINICA DI CURE PALLIATIVE

N° CARTELLA: _____

COGNOME _____ NOME: _____ ETÀ: _____ SESSO: □ M □ F

COMUNE DI NASCITA: _____ DATA DI NASCITA: ___/___/_____

CODICE FISCALE: _____ TESS. SAN.: _____ ESENZIONI: ____ ____ ____

CITTADINANZA: _____ COMUNE DI RESIDENZA: _____

DOMICILIO: _____ CITOFONO: _____ SCALA: __ PIANO: __ TELEFONO: _____

STATO CIVILE:_____ RELIGIONE:_____ SCOLARITÀ:_____ PROFESSIONE: _____

MMG/PLS: _____ TEL: _____

MEDICO DI RIFERIMENTO:_____ INFERMIERE DI RIFERIMENTO:_____

MOVIMENTI

DATA 1° CONTATTO ___/___/_____ DATA COLLOQUIO: ___/___/_____

DATA DIMISSIONE ___/___/_____ DATA PRESA IN CARICO: ___/___/_____

SOSPENSIONE DA ___/___/_____ A ___/___/_____ MOTIVO: □ RICOVERO OSPEDALIERO □ RICOVERO HOSPICE □ ALTRO

SOSPENSIONE DA ___/___/_____ A ___/___/_____ MOTIVO: □ RICOVERO OSPEDALIERO □ RICOVERO HOSPICE □ ALTRO

SOSPENSIONE DA ___/___/_____ A ___/___/_____ MOTIVO: □ RICOVERO OSPEDALIERO □ RICOVERO HOSPICE □ ALTRO

DATA CHIUSURA: ___/___/_____ MOTIVO:

□ 1=DECESSO A DOMICILIO □ 3=TRASFERIMENTO IN HOSPICE □ 5=CAMBIO RESIDENZA □ 7=ALTRO

□ 2= RICOVERO IN OSPEDALE □ 4=TRASF.IN ALTRA STRUTT.RESID. □ 6=CESSAZIONE VOLONTARIA

FIRMA OPERATORE SANITARIO CHE HA CHIUSO LA CARTELLA: _____

FONDAZIONE IRCCS ISTITUTO NAZIONALE DEI TUMORI	CARTELLA ASSISTENZA DOMICILIARE SPECIALISTICA CURE PALLIATIVE	ALL-PRO-P-06

DATA COLLOQUIO: ___/___/_____ OPERATORE CHE HA EFFETTUATO IL COLLOQUIO: _____ FIRMA _____

PROVENIENZA DEL PAZIENTE: □ 1=SERVIZI SOCIALI □ 2= MMG/PLS □ 3=OSPEDALE
□ 4=STRUTT.RESID.EXTRAOSP. □ 5=UTENTE/FAMIGLIA □ 6=ALTRO

PAZIENTE SI TROVA: □ A CASA □ IN OSPEDALE □ IN HOSPICE □ ALTRO NOTE: _____

COMPOSIZIONE DEL NUCLEO FAMILIARE E ABITAZIONE

FAMILIARE	CHI È	TELEFONO	RUOLO	CONVIVE	CONSAPEVOLEZZA
_____	□FAM □BAD □ALTRO	_____	□SI AL COLLOQUIO □REFERENTE □CAREGIVER	□SI □NO	□NO □PARZ. □TOTALE
_____	□FAM □BAD □ALTRO	_____	□SI AL COLLOQUIO □REFERENTE □CAREGIVER	□SI □NO	□NO □PARZ. □TOTALE
_____	□FAM □BAD □ALTRO	_____	□SI AL COLLOQUIO □REFERENTE □CAREGIVER	□SI □NO	□NO □PARZ. □TOTALE
_____	□FAM □BAD □ALTRO	_____	□SI AL COLLOQUIO □REFERENTE □CAREGIVER	□SI □NO	□NO □PARZ. □TOTALE
_____	□FAM □BAD □ALTRO	_____	□SI AL COLLOQUIO □REFERENTE □CAREGIVER	□SI □NO	□NO □PARZ. □TOTALE

CONVIVENTI (ESCLUSO PAZIENTE) ____ ASSISTENZA FAMILIARE 24H: □ SI □ NO □ MINIMALE

N° LOCALI ABITAZIONE: ____ BARRIERE ARCHITETTONICHE: □ 1=NO □ 2= SI

OSSERVAZIONI:

_____
_____
_____
_____

INFORMAZIONE E CONSAPEVOLEZZA DEL PAZIENTE

INFORMAZIONE

□ SI □ PARZIALE □ NO □ NON SI SA

CONSAPEVOLEZZA

□ NESSUNA
□ PENSA DI AVERE UN'ALTRA MALATTIA
□ SA DI AVER AVUTO UN TUMORE MA PENSA CHE I SUOI DISTURBI DIPENDANO DA ALTRA MALATTIA
□ SA DI AVERE UN TUMORE, MA NON PENSA DI ESSERE IN FASE TERMINALE
□ SA DI AVERE UN TUMORE E DI DOVER MORIRE PRESTO
□ NON SI SA

OSSERVAZIONI:

_____
_____
_____

IL LUOGO DELL'ASSISTENZA	PREFERENZA FAMILIARI	VOLONTÀ PAZIENTE
LUOGO DI ASSISTENZA:	□ CASA □ RICOVERO □ NON ESPRESSA	□ CASA □ RICOVERO □ NON ESPRESSA
LUOGO DI FINE ASSISTENZA:	□ CASA □ RICOVERO □ NON ESPRESSA	□ CASA □ RICOVERO □ NON ESPRESSA

AUSILI E ATTREZZATURE	IN USO	DA FORNIRE
	□ COMODA	□ COMODA
	□ CARROZZINA	□ CARROZZINA
	□ LETTO ARTICOLATO	□ LETTO ARTICOLATO
	□ MATERASSO ANTIDECUBITO	□ MATERASSO ANTIDECUBITO
	□ CUSCINO ANTIDECUBITO	□ CUSCINO ANTIDECUBITO
	□ DEAMBULATORE	□ DEAMBULATORE
	□ ALTRO	□ ALTRO

FONDAZIONE IRCCS ISTITUTO NAZIONALE DEI TUMORI	CARTELLA ASSISTENZA DOMICILIARE SPECIALISTICA CURE PALLIATIVE	ALL-PRO-P-06

ASPETTI ANAMNESTICI

PRINCIPALE CENTRO ONCOLOGICO DI RIFERIMENTO _____

CODICE DATA

DIAGNOSI PRINCIPALE _____ _____ ___/___/_____

RECIDIVALE ☐ SÌ METASTASI: ☐ SNC ☐ LINFONODI ☐ POLMONE ☐ OSSA ☐ FEGATO ☐ ALTRO

NOTE _____

TRATTAMENTI EFFETTUATI CHIRURGIA _____

CHEMIOTERAPIA _____

RADIOTERAPIA _____

ORMONOTERAPIA _____

ALTRA TERAPIA _____

ALTRI ELEMENTI ANAMNESTICI

_____
_____
_____
_____
_____
_____
_____
_____

TRATTAMENTI SPECIFICI ATTIVI ☐ NO ☐ SÌ SE SÌ, QUALI: _____

_____

_____

PATOLOGIE CONCOMITANTI

_____
_____
_____

ALLERGIE NOTE _____

MARKERS VIRALI NOTI ☐ HCV ☐ HBV ☐ HIV

TERAPIA IN CORSO PRIMA DELLA PRESA IN CARICO

_____
_____
_____
_____
_____
_____

FONDAZIONE IRCCS ISTITUTO NAZIONALE DEI TUMORI	CARTELLA ASSISTENZA DOMICILIARE SPECIALISTICA CURE PALLIATIVE	ALL-PRO-P-06

PRIMA VALUTAZIONE

DATA ___/___/_____

VITA QUOTIDIANA	☐ 1= AUTONOMO	☐ 2= PARZIALMENTE DIPENDENTE	☐ 3= TOTALMENTE DIPENDENTE
AREA MOBILITÀ	☐ 1= SI SPOSTA DA SOLO	☐ 2= SI SPOSTA SE ASSISTITO	☐ 3= NON SI SPOSTA
AREA COGNITIVITÀ	☐ 1= LIEVI/ASSENTI	☐ 2= MODERATI	☐ 3= GRAVI
AREA COMPORTAMENTALE	☐ 1= LIEVI/ASSENTI	☐ 2= MODERATI	☐ 3= GRAVI
AREA SOCIALE	☐ 1= RETI FORMALI E INFORMALI PRESENTI	☐ 2= RETI FORMALI E INFORMALI IMPARZIALI	☐ 3= RETI FORMALI E INFORMALI ASSENTI
INTENSITÀ ASSISTENZIALE	☐ 1= BASSA	☐ 2= MEDIA	☐ 3= ALTA

MEDICALIZZAZIONE

☐ NESSUNA	☐ URETEROCUTANEOSTOMIA	☐ DRENAGGIO PERITONEALE	☐ NPT	☐ SNG
☐ CVP	☐ TRACHEOSTOMIA	☐ DRENAGGIO TORACICO	☐ NET	☐ MEDICAZIONI
☐ ENTEROSTOMIA	☐ DRENAGGIO BILIARE ESTERNO	☐ CVC/PORT	☐ PEG	

VALUTAZIONE DEI BISOGNI SPIRITUALI

È STATA FATTA UNA VALUTAZIONE DEI BISOGNI SPIRITUALI? ☐ SI ☐ NO

È EMERSA UNA RICHIESTA DI BISOGNI SPIRITUALI? ☐ SI ☐ NO

OSSERVAZIONI

_____
_____
_____
_____
_____
_____

PROBLEMI ATTIVI

_____
_____
_____
_____
_____
_____
_____
_____

CONSIDERAZIONI CONCLUSIVE/ESITO DEL COLLOQUIO:

_____
_____
_____
_____
_____
_____

ATTACHMENT 5

FONDAZIONE IRCCS ISTITUTO NAZIONALE DEI TUMORI	VALUTAZIONE DEL DOLORE IN AMBULATORIO	ALL-PRO-P-01

AMBULATORIO TERAPIA DEL DOLORE

NOME _____ COGNOME _____ DATA _____

SCHEDA DI AUTOVALUTAZIONE DOLORE

Valuti il suo dolore facendo un cerchio intorno al numero che meglio descrive l'intensità del suo dolore

DOLORE ULTIMA SETTIMANA:

DOLORE MEDIO:
Nessun Dolore 0 1 2 3 4 5 6 7 8 9 10 Il peggior dolore possibile

DOLORE PEGGIORE:
Nessun Dolore 0 1 2 3 4 5 6 7 8 9 10 Il peggior dolore possibile

DOLORE ULTIME 24 ORE:

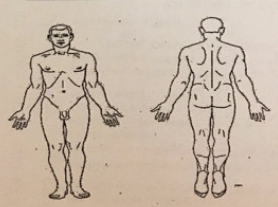
DOLORE MEDIO:
Nessun Dolore 0 1 2 3 4 5 6 7 8 9 10 Il peggior dolore possibile

DOLORE PEGGIORE:
Nessun Dolore 0 1 2 3 4 5 6 7 8 9 10 Il peggior dolore possibile

DOLORE ATTUALE:

Nessun Dolore 0 1 2 3 4 5 6 7 8 9 10 Il peggior dolore possibile

Indichi facendo un cerchio la sede del dolore:



TIQ (Therapy Impact Questionnaire)

DATA DI COMPILAZIONE _____ PAZIENTE

Istruzioni: La preghiamo di rispondere a tutte le domande del questionario facendo una crocetta nella casella ☒ che meglio descrive la sua situazione. Le informazioni riportate verranno tenute strettamente riservate.

NEL CORSO DELLA SETTIMANA QUALI DISTURBI HA AVUTO?

	No	Un po'	Molto	Moltissimo
Dolore	☐	☐	☐	☐
Mal di testa	☐	☐	☐	☐
Insonnia	☐	☐	☐	☐
Problemi nel dormire	☐	☐	☐	☐
Sonnolenza	☐	☐	☐	☐
Vertigini	☐	☐	☐	☐
Tremori	☐	☐	☐	☐
Confusione	☐	☐	☐	☐
Sensazione di debolezza	☐	☐	☐	☐
Sensazione di stanchezza	☐	☐	☐	☐
Mancanza di appetito	☐	☐	☐	☐
Bocca asciutta	☐	☐	☐	☐
Difficoltà ad inghiottire	☐	☐	☐	☐
Nausea	☐	☐	☐	☐
Vomito	☐	☐	☐	☐
Dolore di stomaco	☐	☐	☐	☐
Difficoltà a digerire	☐	☐	☐	☐
Diarrea	☐	☐	☐	☐
Stitichezza	☐	☐	☐	☐
Singhiozzo	☐	☐	☐	☐
Tosse	☐	☐	☐	☐
Difficoltà a respirare	☐	☐	☐	☐
Sudorazione	☐	☐	☐	☐
Prurito	☐	☐	☐	☐
Altro (specificare) _____	☐	☐	☐	☐

SEMPRE NEL CORSO DELLA SETTIMANA

È stato fisicamente male	☐	☐	☐	☐
Ha avuto difficoltà nello svolgere il suo lavoro o i mestieri di casa	☐	☐	☐	☐
Ha avuto difficoltà nello svolgere le solite attività di tempo libero	☐	☐	☐	☐
Ha avuto bisogno di aiuto per mangiare, vestirsi o andare in bagno	☐	☐	☐	☐
Si è sentito triste o depresso	☐	☐	☐	☐
Si è sentito ansioso o spaventato	☐	☐	☐	☐
Si è sentito nervoso, irrequieto o irritabile	☐	☐	☐	☐
Si è sentito insicuro	☐	☐	☐	☐
Ha avuto difficoltà di concentrazione o di attenzione	☐	☐	☐	☐
Ha trovato difficile distrarsi (ad esempio guardando la TV o chiacchierando)	☐	☐	☐	☐
Ha avuto dei momenti di disaccordo in famiglia	☐	☐	☐	☐
Si è sentito isolato dagli altri	☐	☐	☐	☐

ATTACHMENT 6

Palliative Performance Scales (PPS)

PPS Level	Ambulation	Activity & Evidence of Disease	Self-care	Intake	Consclous Level
100%	Full	Normal activity & work No evidence of disease	Full	Normal	Full
90%	Full	Normal activity & work Some evidence of disease	Full	Normal	Full
80%	Full	Normal activity with Effort Some evidence of disease	Full	Normal or reduced	Full
70%	Reduced	Unable Normal jobwork Significant disease	Full	Normal or reduced	Full
60%	Reduced	Unable hobby/house work Significant disease	Occasional assistance necessary	Normal or reduced	Full of conclusion
50%	Mainly Sit/Lie	Unable to do any work Extensive disease	Considerable assistance required	Normal or reduced	Full of conclusion
40%	Mainly in bed	Unable to do most activity Extensive disease	Mainly assistance	Normal or reduced	Full or Drowsy +/- Confusion
30%	Totally Bed Bound	Unable to do any activity Extensive disease	Total care	Normal or reduced	Full or Drowsy +/- Confusion
20%	Totally Bed Bound	Unable to do any activity Extensive disease	Total care	Minimal to sips	Full or Drowsy +/- Confusion
10%	Totally Bed Bound	Unable to do any activity Extensive disease	Total care	Mouth care only	Drowsy or Coma +/- Confusion
0%	Death	-	-	-	-

ATTACHMENT 7

PALLIATIVE PROGNOSTIC SCORE – PaP Score

Possibilità di utilizzo del Palliative Prognostic Score (PaP score) come parametro di valutazione dell'appropriatezza di trattamenti in pazienti con neoplasia in fase terminale. Ad ogni variabile è assegnato un punteggio numerico parziale, basato sul peso relativo del significato prognostico indipendente mostrato da ogni singola categoria nell'analisi multivariata. Permette di dividere i pazienti in tre gruppi prognostici con differenti aspettativa di vita.

DISPNEA	No Si	0 1
ANORESSIA	No SI	0 1
KARNOFSKY	>50 30-40 10-20	0 0 2.5
LEUCOCITI TOTALI	Normali (4.800-8.500) Elevati (8501-11.000) Molto elevati (> 11.000)	0 0.5 1.5
PERCENTUALE LINFOCITI	Normale (20%-40%) Bassa (12%-19.9%) Molto bassa (0%-11,9%)	0 1.0 2.5
CLINICAL PREDICTION SURVIVAL	>12 settimane 11-12 settimane 9-10 settimane 7-8 settimane 5-6 settimane 3-4 settimane 1-2 settimane	0 2 2.5 2.5 4.5 6.0 8.5

Gruppi di Rischio I pazienti sono stati differenziati in tre gruppi a seconda del loro punteggio	**Punteggio Totale PaP-score** Il totale è dato dalla somma dei punteggi singoli, questo può variare da 0 a 17. Più è alto il punteggio, minore è la probabilità di sopravvivenza a 30 giorni.	**Prognosi**
A	0-5,5	Probabilità di sopravvivenza a 30 giorni superiore al 70%
B	5.6 – 11	Probabilità di sopravvivenza a 30 giorni compresa tra il 30% e il 70%
C	11,1 – 17	Probabilità di sopravvivenza a 30 giorni inferiore al 30%

ATTACHMENT 8

Palliative Performance Index (PPI)

Palliative Performance Scale	10 – 20	4.0	4.0
	30 – 50	2.5	
	> 60	0	
Oral Intake	Severely Reduced (≥mouthfuls)	2.5	2.5
	Moderately Reduced (>mouthfuls)	1.0	
	Normal	0	
Edema	Present	1.0	1.0
	Absent	0	
Dyspnea at rest	Present	1.0	3.5
	Absent	0	
Delirium	Present	4.0	4.0
	Absent	0	
	Total		15

ATTACHMENT 9

Richmond Agitation Sedation Scale (RASS) *

Score	Term	Description	
+4	Combative	Overtly combative, violent, immediate danger to staff	
+3	Very agitated	Pulls or removes tube(s) or catheter(s); aggressive	
+2	Agitated	Frequent non-purposeful movement, fights ventilator	
+1	Restless	Anxious but movements not aggressive vigorous	
0	Alert and calm		
-1	Drowsy	Not fully alert, but has sustained awakening (eye-opening/eye contact) to *voice* (≥**10 seconds**)	Verbal Stimulation
-2	Light sedation	Briefly awakens with eye contact to *voice* (<**10 seconds**)	Verbal Stimulation
-3	Moderate sedation	Movement or eye opening to *voice* (**but no eye contact**)	Verbal Stimulation
-4	Deep sedation	No response to voice, but movement or eye opening to *physical* stimulation	Physical Stimulation
-5	Unarousable	No response to *voice or physical* stimulation	Physical Stimulation

8. APPENDIX

Accepted Manuscript

Palliative sedation in terminal cancer patients admitted to hospice or home care programs: does the setting matter? Results from a national multicenter observational study.

Augusto Caraceni, MD, Raffaella Speranza, MD, Elio Spoldi, MD, Cristina Sonia Ambroset, PsyD, Stefano Canestrari, PhD, Mauro Marinari, MD, Anna Maria Marzi, RN, Luciano Orsi, MD, Laura Piva, MD, Mirta Rocchi, RN, Danila Valenti, MD, Gianluigi Zeppetella, MD, Furio Zucco, MD, Alessandra Raimondi, MD, Leonor Vasconcelos Matos, MD, Cinzia Brunelli, PhD

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Reference: JPS 9746

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Palliative sedation in terminal cancer patients admitted to hospice or home care programs: does the setting matter? Results from a national multicenter observational study.

Augusto Caraceni[1] MD, Raffaella Speranza[2] MD, Elio Spoldi[3] MD, Cristina Sonia Ambroset [4] PsyD, Stefano Canestrari[5] PhD, Mauro Marinari[6] MD, Anna Maria Marzi[7] RN, Luciano Orsi[8] MD, Laura Piva[9] MD, Mirta Rocchi[7] RN, Danila Valenti[10] MD, Gianluigi Zeppetella[11] MD, Furio Zucco [12] MD, Alessandra Raimondi[1] MD, Leonor Vasconcelos Matos [13] MD and Cinzia Brunelli[1,14] PhD on behalf of the Italian Society of Palliative Care Study Group on Palliative Sedation in Adult Cancer Patients.

Dr.Augusto Caraceni, Raffaella Speranza and Elio Spoldi are equally first author of the present paper

1. Palliative Care, Pain Therapy and Rehabilitation Unit, Fondazione IRCCS Istituto Nazionale dei Tumori, Milano, Italy.
2. Italian Society of Palliative Care, Milan, Italy
3. AO Cremona Hospital, Hospice and Palliative Care Unit, Cremona, Italy
4. Associazione VIDAS, Psychology Unit, Milan, Italy
5. Alma Mater Studiorum University of Bologna, Department of Legal Studies, Bologna, Italy
6. Hospice "il Nespolo", Airuno (LC), Italy
7. Hospice "Casa Madonna dell'Uliveto", Albinea (RE), Italy
8. AO Ospedale Maggiore Crema, Palliative Care Unit, Crema, Italy
9. AO San Paolo Hospital, Palliative Care Unit, Milan, Italy
10. AUSL Bologna, Palliative Care Network, Bologna, Italy

11. Hospice "Nicola Falde", Santa Maria Capua Vetere (CE), Italy

12. AO G. Salvini, Hospice and Palliative Care Unit, Garbagnate Milanese (MI), Italy

13. Hospital Sao Francisco Xavier, Department of Medical Oncology, Lisbon, Portugal,

14. European Palliative Care Research Center (PRC), Department of Cancer Research and Molecular Medicine, Faculty of Medicine, Norwegian University of Science and Technology (NTNU), Trondheim, Norway.

Running title: Palliative sedation in home care and hospices

Tables 3

Figures 3

References 49

Word count: 3362

Correspondence should be addressed to:

Brunelli Cinzia, PhD, MSc.

Palliative Care, Pain Therapy and Rehabilitation Unit

Fondazione IRCCS Istituto Nazionale dei Tumori

Via Venezian 1

20133 Milano

Milano -Italy

Tel. +39-02-23903387 Fax +39-02-23903393

e-mail: cinzia.brunelli@istitutotumori.mi.it

http://www.istitutotumori.mi.it/

http://www.ntnu.edu/prc/prc

ABSTRACT

Context Few studies regarding palliative sedation (PS) have been carried out in home care (HC) setting. A comparison of PS rate and practices between hospice (HS) and HC is also lacking.

Objectives Comparing HC and HS settings for PS rate, patient clinical characteristics before and during PS, decision-making process and clinical aspects of PS.

Methods 38 HC/HS services in Italy participated in a multicenter observational longitudinal study. Consecutive adult cancer patients followed till death during a four-month period and undergoing PS were eligible. Symptom control and level of consciousness, , were registered every 8h to death.

Results 4276 patients were screened, 2894 followed till death and 531 (18%) underwent PS. PS rate was 15% in HC, 21% in HS ($p<0.001$). Principal refractory symptoms were delirium (54%) and dyspnea (48%), respectively more common in HC ($p<0.001$) and HS ($p=0.03$). Informed consent was not obtained in 72% of patients but achieved by 96% of families. Midazolam was the most used drug, (94% HS vs 75% HC, $p<0.001$) mainly by continuous infusion (74% HC vs 89% HS, $p<0.001$). PS duration was <48h in 67% of patients. Hydration during PS was less frequent in HC (27% vs 49%, $p<0.001$). In the 8h before death, consciousness level was "unrousable to mild physical stimulation" in 81% and symptom control "complete" in 89% of cases.

Conclusion Our results show feasibility of PS in HC and HS, and suggest setting differences in rates, indications and practice of PS, possibly related to patients selection or care organization.